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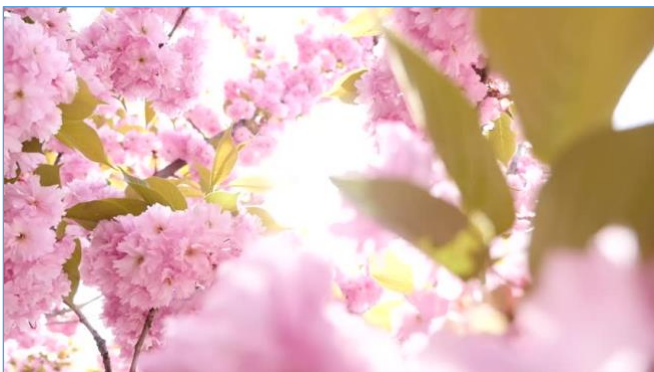
Scleroderma

New Zealand support group

SPRING 2024

Greetings to you all...

Welcome to the Spring edition of our Scleroderma Newsletter...



Kia ora koutou, nau mai haere mai, greetings to you all. We hope everyone is doing well and have recovered from all the winter colds and flu this year.

In this edition we warmly welcome our new members who have recently been diagnosed with scleroderma. We hope you will find some of the articles in this newsletter useful and informative.

We hear first from Jenny Andrews with the Presidents report. Jenny keeps us up to date with what's happening within our community.

We have an interesting article on Intravenous immunoglobulin (IVIG), a therapy particularly effective as add-on treatment to ease skin, muscle and digestive

symptoms in people with scleroderma, according to a recent review study.

There is an article on interstitial lung disease diagnosis and treatment.

Helen shares with us her experience on packing drugs for travel and also shares how she explains her diagnosis to others.

Perry shares his blog on 10 ways to find joy and I've put in an article on the emotional impact of a chronic illness diagnosis and how to navigate your feelings.

We have our regular Members News and Updates from our different support groups.

Spring is finally here and daylight saving will start on the **29th September** this year. I'm looking forward to the warmer days and longer daylight so I can do more outside in the garden.

Take care everyone.
 Nga mihi,
Tina and Jenny



Presidents Report:

SPRING 2024



A very big welcome to all our new members. There have been a number of you throughout the country and we wish you all the best. Hopefully knowing that there is a community out there with folks going through a similar journey it will make things a little easier for you.

My condolences to all those who have lost loved ones over the past few months.

We had our AGM the end of June and welcomed along two new members. Thank you to Perry Bray and Helene Sunitsch for committing to help Scleroderma New Zealand by joining the committee. Everyone else stayed on from last year which was wonderful. I really appreciate the time you all put into working to make Scleroderma New Zealand a go to place for all those affected by the condition.

We can see light at the end of the tunnel as we head into Spring. I am seeing a lot of lambs around the place which always makes my heart melt. Makes me worry about the poor wee things though when we have had hail and some very light snow this morning. Meanwhile Storm, my dog and I are rugged up nice and warm inside just looking out at it all.



I enjoyed the National Zoom Meeting that Perry Bray from Wellington organised. It was really lovely to see some new faces on there and some good old familiar ones also. It is very humbling hearing from all those who are going through a very tough time. I really wish we had a magic wand to get rid of all the pain and misery out there but sadly that cannot happen. All we can do is be there for you all and listen and share experiences. Perry is doing a wonderful job with the regular zoom meetings. This was the first one I was able to attend and I was very pleased I did.

Thank you to all those who have written something for us to add to the newsletter. We really appreciate your input and love seeing your personal stories and achievements, your holidays and gardens, hikes and craft work. Anything you wish to share here is amazing and very welcome.

We down in Winton are about to run our 41st Spring Flower show here in a couple of weeks. I see there are lots happening around the country also, so if you get a chance to check them out try and do so. A lot of work goes into them and the flowers are incredible. Maybe don't attend if you have allergies though as the scent is divine in the hall. And do rug up as the temperatures have to be low to keep the flowers looking stunning. I have always got my big coat, hat and gloves on working there. We do get rewarded with yummy soup, savouries, sandwiches and sweets. Sooooo worth giving up a few days of my time.

Heather Milligan, I love the kiwi ingenuity you came up with to keep your feet warm while using your Revitive Circulation Booster. What a fabulous idea. Learn what Heather did on page 5.

Thanks to Tina's son Ian for his fun jokes on page 18. Nice to see the photos of him there also. We are proud to have Ian as part of our Scleroderma Family.

Thanks to Perry for sharing his blog with us. Always a great read. Thank you Helen Parsons for your writing on packing with drugs, and also your diagnosis explanation. I am in the process of planning our 2025 adventure so have to be very organised with my medication to make sure I have 6 weeks' worth that I can take and still have enough for when I get home. Does anyone else have any pointers on this or packing in general. I am always looking at ways to simplify my packing as I am renowned to over pack.

Until next time

Take care all and stay warm.

Jenny (and Storm) ☺



Support Crew

Making it easy to give a hand

Support Crew is a FREE online help roster that easily co-ordinates meals and support for family and friends in need. Create a Support Page for yourself or someone else.

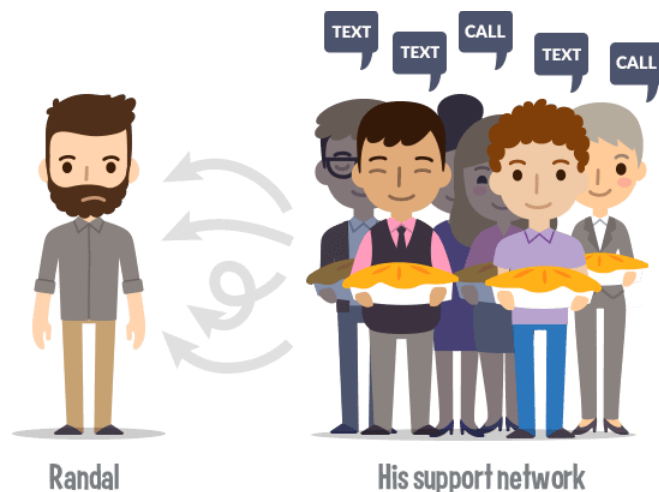
Check out the website here shared with us by Nicky. Thanks heaps Nicky

<https://www.supportcrew.co/>



Support Crew makes it easy to ask for help...

...by creating a private place for those in need to easily ask for the help they need, so they feel less overwhelmed and can focus on the things that matter.



The old way...

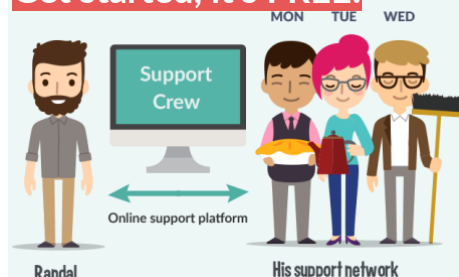
Knowing how to give a hand shouldn't be this hard right?

When dealing with a life event, we struggle to ask for help and our friends don't know how to help.

The new way...

With Support Crew, it's simple, personal, and easy for everyone.

Get started, it's FREE!



to know how to help...

...by providing a place for the support network to confidently know how to help those in need, so they feel less helpless and more connected.



IVIG effective in easing range of scleroderma symptoms

22/8/2024

Therapy particularly effective as add-on treatment
by [Patricia Inácio, PhD](#) | August 13, 2024



[Intravenous immunoglobulin](#) (IVIG) eases skin, muscle and digestive symptoms in people with [scleroderma](#) (SSc), particularly when used as an add-on therapy, according to a recent review study.

While no improvements were seen in respiratory function, IVIG still led to stabilization of these symptoms.

The findings “suggest that IVIG may be effective in treating a range of organ-specific manifestations with minimal side effects, thus making it a potentially attractive therapeutic option for SSc,” the researchers wrote.

The review, “[Role of intravenous immunoglobulins in systemic sclerosis \(SSc\): A systematic literature review](#),” was published in *Seminars in Arthritis and Rheumatism*.

Scleroderma, also called systemic sclerosis, is an autoimmune disease that causes the hardening and fibrosis — thickening or scarring — of the skin. Often, scleroderma also affects internal organs, posing a risk of more severe outcomes.

Studying IVIG and scleroderma

IVIG has been a standard treatment in several autoimmune diseases, such as [myasthenia gravis](#). IVIG delivers specific antibodies purified from healthy people to help neutralize self-reactive antibodies in a patient’s bloodstream.

In SSc, “reports of [IVIG’s] efficacy have been variable, and its use across multiple organ manifestations of SSc has not been comprehensively reviewed,” the researchers wrote.

The researchers, from The University of Melbourne, Australia, conducted a review of studies published from January 2003 to April 2024, looking the effects of IVIG on several organs affected by SSc.

The review considered 12 studies, covering a total of 354 SSc patients. Most patients were women (83%), with an average age of 53.4 at time of IVIG start. Different types of studies were part of the analysis, including a clinical trial,

pilot studies, and an open-label study (one in which both investigators and patients are aware of what drug or intervention is being assessed).

Diffuse cutaneous systemic sclerosis (dcSSc) was the most common [SSc type](#), found in 76% of the patients studied, followed by limited cutaneous SSc (lcSSc), which affected 23%. About a third of patients (31.6%) also presented other SSc symptoms, most commonly myositis, or muscle inflammation and weakness.

The most common dose of IVIG was 2 g/kg/month administered over two to five days. In six studies, IVIG was given together with [immunosuppressants](#), including cyclophosphamide, corticosteroids, azathioprine, and methotrexate.

Seven studies reported side effects associated with IVIG use; the majority were minor. They included nausea, headache, or fever, and did not result in treatment withdrawal. Ten patients withdrew from their studies due to other side effects, such as acute kidney injury or high blood pressure.

The review documented 18 outcomes, which were grouped into five categories: skin, respiratory, musculoskeletal, digestive tract, and other, which included clinical improvements reported by patients and physicians and the benefit of corticosteroid sparing.

Overall, IVIG treatment was effective at easing skin thickening, assessed mainly by the modified Rodnan Skin Score, and joint pain. Among the studies assessing the impact on the musculoskeletal system, one showed a lower percentage of patients with muscle pain after treatment. A study showed muscle weakness was lessened in 24% of patients, and another showed this benefit in 92%.

IVIG also had positive effects on digestive symptoms, such as less intense and less frequent acid reflux. An easing of abnormal bowel symptoms, as well as reduced bloating and better social functioning and emotional well-being, were also reported after IVIG.

Two of five studies assessing patient-reported outcomes showed that IVIG led to a marked improvement in overall health. One study showed that all patients treated with IVIG achieved remission of muscle disease, compared with 82% of controls given a placebo. Time to relapse of muscle disease also was longer for IVIG patients compared with those on a placebo — a median of 23 months vs. 12 months.



IVIG effective in easing range of scleroderma symptoms continued...

Corticosteroid use was significantly reduced with IVIG, according to data from three studies.

While no significant easing of respiratory symptoms was observed with IVIG, the treatment led to a stabilization in pulmonary function tests, which “may be considered a positive outcome in itself,” the researchers wrote.

While the findings support the potential of IVIG for easing skin, musculoskeletal and digestive symptoms in SSc, the evidence stems from “mostly non-randomised studies with small sample sizes at high risk of bias,” the researchers wrote. Randomized studies randomly assign participants into an experimental group or a control group.

“High-quality, randomised clinical trials would assist to confirm the findings of this review,” they concluded

Source: [IVIG effective in easing range of scleroderma symptoms - Scleroderma Queensland](#)

Revitive Circulation Booster By: Heather Milligan

At the Zoom meeting on 31st August, Richard mentioned that he had started using a Revitive Circulation Booster. He commented that it did appear to be helping him. At a Southland Scleroderma meeting about 10 years ago one of the attendees bought her device for us to try. It was certainly a weird feeling having pulses travelling up your legs from your feet on the device. I did purchase a machine and have tried to use it every day, the pulses still feel weird, even after all this time. I don't know whether it has helped my leg circulation but I think it cannot do me any harm.

Before I first used the device I read the instructions which said I would get the best result by putting bare feet on each of the footpads. An immediate problem as my feet do get cold very quickly even on a warm day. Problem solved by purchasing a pair of cheap slippers and cutting the soles out (photo attached), and when using the machine put the slippers on with naked soles and the slippers do keep my feet warm.

You can purchase a machine off Trade Me/Harvey Norman/Chemists.

From the Revitive website.

- **How Revitive works**
- Revitive Circulation Booster works by contracting and relaxing your lower leg muscles to increase the leg circulation. Using Electrical Muscle Stimulation (EMS), also known as Neuromuscular Electrical Stimulation (NMES), and Revitive's patented wide-pulse waveform, Revitive Circulation Booster stimulates the leg muscles to pump the calf muscles and increase oxygen-rich blood to the legs and feet.
- Revitive has been developed and tested by physiotherapists and cardiovascular surgeons, and is clinically proven to increase circulation in the legs and feet during use
- Actively improve leg circulation.
- Reduce leg aches & pains.
- Reduce cramp.
- Reduce swelling.
- Increase walking distance before pain.

Do not use if:

- You are fitted with an electronic implanted device such as a heart pacemaker or Automatic Implantable Cardioverter Defibrillator (AICD)
- You are pregnant.
- You are being treated for, or have the symptoms of, an existing Deep Vein Thrombosis (“DVT”)



Spotlight on Interstitial Lung Disease Diagnosis and Treatment on ILD Day, Sept. 18

NEWS PROVIDED BY

The Pulmonary Fibrosis Foundation

Sep 09, 2024, 10:15 ET

CHICAGO, Sept. 9, 2024 /PRNewswire/ -- Nine leading patient organizations are uniting to present the fourth annual ILD Day on Wednesday, Sept. 18, to raise awareness and understanding of interstitial lung disease (ILD) and pulmonary fibrosis (PF). ILD encompasses a large group of more than 200 diseases characterized by inflammation and/or scarring in the lungs, making it difficult to breathe and get oxygen to the bloodstream.

"Interstitial lung disease is a debilitating condition that's often difficult to diagnose, making early detection crucial," said Scott Staszak, President and CEO of the Pulmonary Fibrosis Foundation. "If you or a loved one experiences a persistent dry cough, shortness of breath and fatigue, see a pulmonologist immediately. Treatments to slow the progression, along with resources and support, are available."

More than 250,000 Americans are living with ILD and 50,000 new cases are diagnosed annually. Pulmonary fibrosis can be seen in many types of ILD, and the damage caused by ILD can be irreversible and worsen over time.

Symptoms and Risk Factors of ILD

The most common symptoms of ILD include shortness of breath, dry cough and fatigue. Other symptoms include chest discomfort, "clubbing" of the fingertips, loss of appetite and unexplained weight loss.

Causes of ILD include the use of certain medications, radiation to the chest, and environmental and occupational exposures. In addition, patients with some diseases, such as rheumatoid arthritis, scleroderma, myositis, including dermatomyositis and polymyositis (DM and PM), sarcoidosis and Sjögren's, may develop ILD. A specific form of ILD, namely idiopathic pulmonary fibrosis (IPF), primarily occurs in older individuals.

Educational Webinar

An educational webinar, "The journey to diagnosis: Process, evaluation, and your care team," will be held at 12 p.m. CDT on Wednesday, Sept. 18. The presentation will address how doctors recognize ILD and find the right diagnosis for each individual. Important information about

the roles of your care team and how to advocate for yourself will be provided. The webinar will be presented by Dr. Sonye Danoff, pulmonologist with Johns Hopkins Medicine and Senior Medical Advisor, PFF Care Center Network. Registration is available [here](#). The webinar will be recorded and published on the [PFF YouTube channel](#).

ILD Day is a collaboration between the Pulmonary Fibrosis Foundation, Arthritis Foundation, Foundation for Sarcoidosis Research, The Myositis Association, PF Warriors, National Scleroderma Foundation, Scleroderma Research Foundation, Sjögren's Foundation and Wescoe Foundation for Pulmonary Fibrosis.

To register for the ILD Day webinar or for more information about ILD, visit ILDDay.org.

About ILD Day

ILD Day was created to drive awareness of interstitial lung disease (ILD) and is recognized annually in September. It is presented by a collaboration of nine organizations representing patients affected by interstitial lung disease: [Pulmonary Fibrosis Foundation](#), [Arthritis Foundation](#), [Foundation for Sarcoidosis Research](#), [The Myositis Association](#), [PF Warriors](#), [National Scleroderma Foundation](#), [Scleroderma Research Foundation](#), [Sjögren's Foundation](#), and [Wescoe Foundation for Pulmonary Fibrosis](#). For more information, visit ILDDay.org.

About the Pulmonary Fibrosis Foundation

The mission of the [Pulmonary Fibrosis Foundation](#) is to accelerate the development of new treatments and ultimately a cure for pulmonary fibrosis. Until this goal is achieved, the PFF is committed to advancing improved care of patients with PF and providing unequalled support and education resources for patients, caregivers, family members, and health care providers. The PFF has a four-star rating from Charity Navigator and is an accredited charity by the Better Business Bureau (BBB) Wise Giving Alliance. The Foundation has met all of the requirements of the National Health Council Standards of Excellence Certification Program® and has earned the Guidestar Platinum Seal of Transparency. For more information, visit pulmonaryfibrosis.org

Source: [Spotlight on Interstitial Lung Disease Diagnosis and Treatment on ILD Day, Sept. 18 \(prnewswire.com\)](http://prnewswire.com)



The Emotional Impact of a Chronic illness Diagnosis: How to Navigate Your Feelings

It was great to be able to catch up with our members recently on Zoom, not just were we able to meet lots of lovely new members but we also got to be able to put faces to names. For some of our members who have recently been diagnosed with Scleroderma, we understand how this diagnosis can be very over-whelming for you. Talking with others can often help, and having a support group is always good. To know that there are others who have Scleroderma and that you are not alone, hopefully may give you strength.

I found this article which I hope may be helpful to our members who are at the start of their Scleroderma journey...

Chronic illnesses can impact a person's physical and emotional well-being. The emotional impact of living with a chronic illness diagnosis can be incredibly challenging. The shock, disbelief, and sadness of a chronic illness diagnosis can be overwhelming, so it's important to find ways to cope with these emotions.

Here are some tips for dealing with the emotions that can arise from receiving a chronic illness diagnosis.

Acknowledge your emotions

Try not to ignore what you're feeling. Feeling overwhelmed, scared, or even angry after receiving a chronic illness diagnosis is completely okay. You may feel like your life has taken a complete 180 and may experience loss or grief for your pre-diagnosis life. All these feelings are normal and valid, so allow yourself to experience and express them.

Ways to express your feelings

Here are a few examples of how to express your emotions healthily:

- Talk to a friend or family member
- Join a support group
- Seek counseling
- Jot down your feelings in a journal
- Practice mindfulness

Educate yourself about your chronic condition

Research your invisible illness, like symptoms, treatment, and potential complications, to help you better understand your condition. Educating yourself about your chronic illness can also help you make informed decisions about your care and treatment while empowering you.

There are several resources available to help you learn about your condition. Your healthcare provider may be

your primary source of information, but you can also look for reputable sources of information online. However, be cautious about where you gather information to avoid unreliable sources that spread misinformation.

Connecting with others

Chronic illness can feel isolating, but you are not the only one facing challenges. Connecting with others living with similar conditions can give you support and validate your experience. For example, support groups, whether in person or online, offer a sense of community and a safe space to share your experiences with others who understand your situation.

Practice self-care

Taking care of yourself is essential for managing the emotional impact of a chronic illness. Self-care can exist in many forms, but it's essential to do activities that bring you excitement and relaxation.

Some examples of [ways to practice self-care](#) include the following:

- Practice gratitude
- Catch enough Zs at night
- Focus on positivity
- Take part in relaxing activities, like meditation, breathing exercises, or muscle relaxation
- Stay connected to loved ones

Exercise and healthy eating are also important aspects of practicing self-care. Regular exercise can improve your physical and mental well-being, reduce stress and anxiety, and enhance your quality of life. In addition, a healthy, balanced diet can help manage symptoms such as fatigue, joint pain, and inflammation, common chronic illness symptoms.

Building a support network

After receiving a chronic illness diagnosis, it's best to have people you can lean on for emotional support. Your support network may include family members, friends, healthcare providers, and support groups. Let your loved ones know what you need from them- practical help, emotional support, or just someone to listen to.

Receiving a chronic illness diagnosis can be a challenging and emotional experience. It is normal to become overwhelmed with emotions of fear, sadness, and anger. While it's okay to experience these feelings, you should have outlets to relieve your emotions. Always remember that you are not alone in this journey; resources are available to help you navigate this challenging time.

Source: [The Emotional Impact of a Chronic Illness Diagnosis: How to Navigate Your Feelings — Chronius Health](#)



Scleroderma and stem cell transplants

Report by: Heather Milligan

Scleroderma and stem cell transplants presentation by Scleroderma Victoria Australia Incorporated which began in 1979 to support people with Systemic Sclerosis.

<https://sclerodermavictoria.com.au/>

They have Education seminars via Google Meets monthly. New Zealanders can join in.

The September event was held on Saturday 14 of September. The topic was Scleroderma and stem cell transplants. The speaker was Dr Marie Hudson, a rheumatologist and epidemiologist affiliated with the Jewish General Hospital and the Lady Davis Institute in Montreal. She is also an associate professor and member of the Division of Experimental Medicine in the Department of Medicine at McGill University. Her research focuses on systemic autoimmune rheumatic diseases(SARD).

Dr. Hudson's current research focuses on cellular therapies for scleroderma. Among several projects, she is leading a CIHR-funded Phase I/II trial of mesenchymal stromal cells in severe scleroderma.

The main points of her talk were.

She was unequivocal that Stem cell transplant does not cure Scleroderma, if successful it does slow the progression, but you will still be left with the ravages that scleroderma has taken on your body. If all goes well, it is important to manage your expectations of the results of the transplant. This was reinforced by surveys of transplanted patients that they did feel well, but their mental health thinking about their transplant was not as positive as they had hoped for a cure.

There is rigorous testing before a transplant – the classic saying 'you must be ill enough for a transplant but fit enough to cope with the toxicity of the transplant'. Of 1500 patients who would be suitable for a transplant, after testing only 85 would be selected. Your heart must be exceptional, no smoking and the ideal is to have a transplanting teams who are knowledgeable about Scleroderma. Dr Hudson's patients travel from Montreal to Ottawa for the expertise of a transplant centre there.

Using the only procedure available is Hematopoietic stem cell transplant (HPSCT), sadly over the first 100 days after transplant 5 – 10% of patients will die.

She only recommended transplant for those with diffuse cutaneous systemic sclerosis, those with limited cutaneous systemic sclerosis 'are not affected by scleroderma enough!'.

At the moment there is only Hematopoietic stem cell transplant (HPSCT) available..

https://www.cochrane.org/CD011819/MUSKEL_stem-cell-transplantation-treatment-systemic-sclerosis

There is research into mesenchymal stem cells (MSCs) .

<https://stemcellres.biomedcentral.com/articles/10.1186/s13287-022-02786-3>

Dr Hudson feels due to it being less toxic feels it is a promising technique.

Also in its infancy is CAR (Chimeric Antigen Receptor) T cell therapy, it is promising but premature.

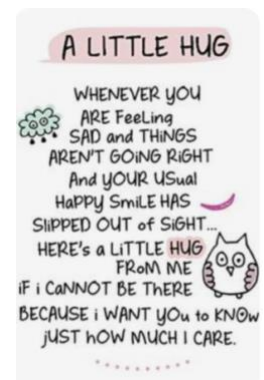
<https://www.sruk.co.uk/about-us/news/cancer-autoimmunity-could-car-t-cell-therapy-cure/>

'Heather' from Australia commented that she had a transplant in 2018, was extremely ill and was in intensive care for a number of days. She does feel well now and feels if it was not for the transplant she would be dead as her scleroderma was uncontrollable, she had been given many medications (including Mycophenolate Mofetil) leading up to the transplant. She did have trouble coping initially as she had been left with the impression that she was cured.

Good to hear the questions and answers from the participants at the end.

Thank you again to Scleroderma Victoria and Dr. Marie Hudson for the time and expertise.

Heather Milligan



Members Stories:

Packing drugs for travel:

Written by Helen Parsons

I thought I'd record my experience of packing my drugs for travel. Most of us will have had to do this. I fly to UK in a week or so. I always have detailed lists for all my packing. What goes into my checked-in baggage, what goes into my cabin bag.

I also have a small, pretty backpack with my technology in it, and a dark brown leather handbag with my travel meds. One of these can fit into the cabin bag so that I comply with the pieces and weight requirement.

But it's the counting of the pills that flummoxes me. 1 tab in early morning, each day of the week for 3 weeks, that's easy. That adds up to 21 tabs.

But what about 4 tabs, 3 times daily, for 3 weeks (which is 21 days I think), equals . . . what?????

And I do this sort of arithmetic for six different medications.

Then I need some separately for the travel days. Again counted out in detail, and deposited into other tiny bags that I'll keep in that brown leather handbag near me.

One of my big things is that I also want emergency supplies of all my meds.

Roger went off to the pharmacy to pick up my new lot of drugs. He came home with a truckload full.

I mentioned to him that I was travelling with a duplicate three weeks of meds. He was appalled.

However, he said he understood when I pointed out that I could take just one spare week of drugs, but that mightn't be helpful if one of us had a medical emergency.

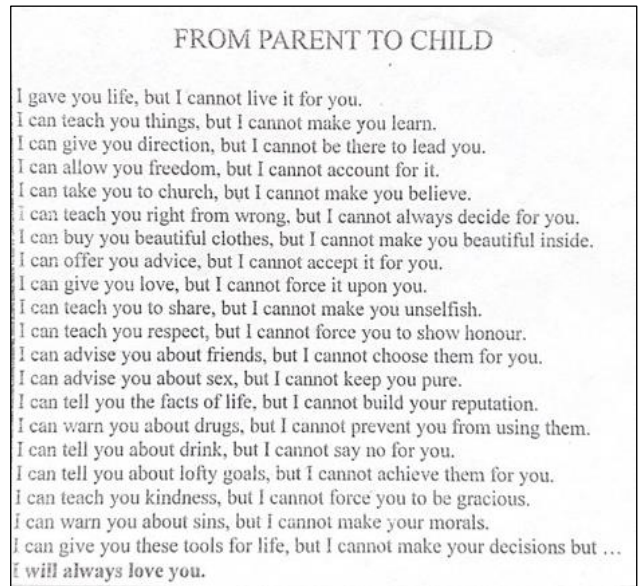
I read all the stories of people from Aotearoa who were held up overseas during covid without medications. I'd be horrified to be in that situation.

But oh dear, as I write this I am uncertain if I have calculated the meds that I'll put into my dinky weekly dispensers. Four of them. I'm still using those while I'm at home.

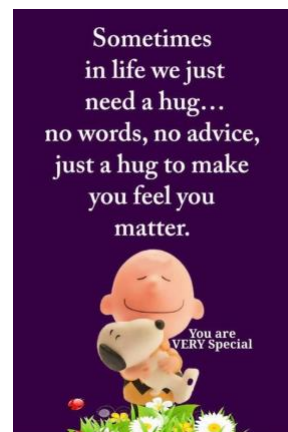
I can't for the life of me work out if I counted them in. I feel I'm going nutty. Do I really have to do all that arithmetic again? *Helen Parsons*



Sent in by Heather Barker – Thanks Heather



Thanks Betty for sharing



Members Stories:

Diagnosis Explanation:

By Helen Parsons

Roger and I were talking
He'd just read about a chap who was talking of his prostate cancer experience with the same surgeon who looked after Roger two decades ago. The chap talked of the effect the initial diagnosis had on him and how it affected his family. Also he said he kept the news close to himself and his family.

Well I had a different reaction when I received my shock Diffuse Scleroderma diagnosis almost four years ago. I was 75 years of age. I was told I might have another five years to live.
My concrete-like skin, all over my body was having a big effect on my life style. I accepted the drug regime straight away. And these drugs have helped me immensely.

But what I wanted to say here is that I wrote a short email to all my large family, four sisters, cousins, and to my friends.
I quoted from the letter of diagnosis that my rheumatologist had sent to my GP.

I found it helpful to use some of the exact terms that he had used. Particularly because some of my sisters are sticklers for accuracy. One of them said to me "but you had said you had"
And I was able to reply that, no that was an initial suggestion by the specialists, but that all the detailed testing, and my extensive symptoms had confirmed Diffuse Scleroderma as my label.

I found that my simple email was so helpful in getting out the details that I wanted people to have. Everyone was matter of fact and kind. (I left out the lifespan bit.)
I understand that many people would not want to be as open as I was. But I do have a theory that it is easier if friends and family are told something – of my choosing, rather than having to second-guess, and having to wonder how to ask how things are going.

Helen Parsons



Teddy Picture sent in by Heather Barker



**SOMETIMES
YOU FORGET
YOU'RE
AWESOME
SO THIS
IS YOUR
REMINDER**



A Little Poem For Seniors, so true it hurts!

Another year has passed And we're all a little older.
Last summer felt hotter And winter seems much colder.
There was a time not long ago When life was quite a blast.
Now I fully understand About 'Living in the Past'
We used to go to weddings, Football games and lunches..
Now we go to funeral homes And after-funeral brunches.
We used to go out dining. And couldn't get our fill.
Now we ask for doggie bags, Come home and take a pill.
We used to often travel! To places near and far.
Now we get sore asses From riding in the car.
We used to go to nightclubs And drink a little booze.
Now we stay home at night And watch the evening news.
That, my friend is how life is, And now my tale is told.
So, enjoy each day and live it up...
Incredible Before you're too damned old!

When my arms can't reach people who are close to my heart...
I always hug them with my prayers.



www.lampoodle.com

Thanks Betty



Members Stories:

10 Ways to Find Joy...

July 16th, 2024 by Perry

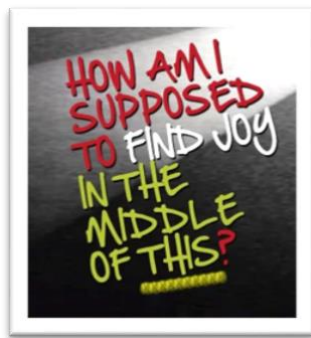
As featured on my blog ([The life and times of Perry... Are you in the game or are you watching from the sidelines...](#))

Being diagnosed with Scleroderma can certainly have one questioning "How am I supposed to find joy in the middle of this?" let alone when things don't go as one envisaged.

10 Ways to FindJoy

July 16, 2024 by [Perry](#)

I was recently emailed a link from [Self-Manage Scleroderma](#) who created a web based self-management program called 'Taking Charge of Systemic Sclerosis (TOSS)'.



This program was designed to help those suffering with Scleroderma learn about the disease, manage their symptoms and learn strategies to help advocate for themselves.

It explores 10 ways in which we can find joy as we navigate a number of 'new' normals along our health journey with a rare, incurable autoimmune disease.

The thing is, sometimes it can be extremely hard to find joy in the middle of everything that you are going through. And even those that have a strong faith can succumb to feelings of helplessness, especially when fatigue gets on top of them – sucking the very life that joy can bring out of them.

So, maybe some of the below helpful ways to find joy will help combat those times when you feel despondent and barely able to get out of bed through lack of energy or motivation.

1. Every day, do something that reaffirms the beauty and joy of living.

Take time to look around and you'll find plenty of proof that beauty is everywhere. Have your morning cup of coffee in sight of the sunrise, or make it a point to see the sunset. Nature brims with the miracle of life — get outside and soak it in.

Why not go for a walk through a park listening for birds, watch clouds in a robin's-egg-blue sky, go barefoot in lush grass (if it is not too cold), or skip stones on a lake. Stop to smell those roses, and while you're at it, buy some fresh flowers for the house.



2. Do something!

A feeling of helplessness in the face of tragedy or human need and suffering contributes to stress. Volunteerism is one of the best ways to give activity purpose, and is therapeutic. In helping others, you help yourself.

There's a lot to be said for just practicing random acts of kindness. Recent research found that a "joy centre" of the brain thrills more to unanticipated delights than to what's expected.

So, maybe in the next day or so why not surprise someone with a small gift. The payoff for you is experiencing the joy of giving.

3. Turn off the television and radio news.

Reliving the horror of 9/11 in documentary form can open old wounds. Choose instead to rent a feel-good movie or watch family videos you haven't seen in a while. Or pull out those scrapbooks and albums. Gather everyone around the stereo for an old-fashioned life-affirming radio show. Even just turning up some favourite old tunes can rejuvenate the spirit. Sing along!

4. Get to know your neighbours.

A sense of neighbourhood and community increases feelings of security and connectedness. Don't let the month of September become tainted forever, or allow loss and grief to steal your joy.

Welcome autumn with new neighbourhood traditions: Plan a block-party cookout or chili cook-off, organise a pre-holiday cookie exchange, or host a multi-family garage sale. It need not be anything elaborate. Share a batch of cookies with the folks next door or just sit on the front porch talking with the neighbours. Friendships develop in the details of daily living.



Members Stories:

10 Ways to Find Joy continued...

July 16th, 2024 by Perry

5. Laugh.

It really is the best medicine, reducing anxiety, depression, and fear. In fact, studies show that laughter is one of the best ways to let out negative emotions without causing harm.



Buy a funny book and chortle away, tell silly knock-knock jokes with the kids, invent a stupid pet trick, or watch a screwball comedy the whole family will enjoy.

6. Start and end the day on a positive note.

Your mother always told you to, and the advice is still great: Count your blessings. When you wake up, start your day with a thankful thought. Ditto at bedtime. If you feel down during the day, actually make a list of the good things in your life.

Meditate, sing, practice yoga, light a candle – find small positive rituals that centre you with good thoughts and positive energy as you begin and close the day.

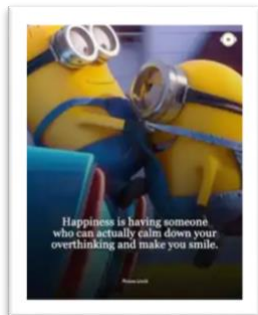
7. Don't allow anger and rage to rule your life.

Misdirected anger isn't healthy. Consciously replace churning emotions with serene thoughts. Think of a particularly tranquil time at the ocean, or imagine yourself in a favourite soothing place.

Find healthy ways to let off steam: exercise, make music, garden, paint, write out your thoughts in a journal. If you continue to feel overwhelmed or undermined, you can turn to prayer or professional assistance for help in handling upsetting feelings.

8. Think of something that makes you smile

Before you get out of bed and brush your teeth, get your mental and visual focus on something that will warm your heart. Try putting a favourite picture – hospital photos of your new-born, the brand-new kitten,



a perfect moment on a family vacation – on your bedside table. Look at it first thing in the morning.

Starting off your day in a positive frame of mind will set your spiritual metabolism for the rest of the day. Smiles not only exercise muscles that fight frown lines, they actually boost your immune system.

9. Be forgiving.

Forgiveness is an act of the will, an action you can take even when your heart and feelings seem to be lagging behind in bitterness. It might be impossible to forgive actual perpetrators, but you can hope and pray for transformation in them.

In your own life, give up grudges and let go of old toxic memories. Reconcile with estranged friends and family members if you can, and commit yourself to giving others the measure of forgiveness you would like extended to you. Don't sweat small grievances.

10. Nurture your family spirit.

We live in a different world now, a world that needs love more than ever. Show your commitment to those you love in word and deed. "I love you" means a lot, and so do the actions that make the words more than greeting-card sentiment. So say it, show it, and hug a lot.

Strengthening family ties cultivates stability in your home. See and call out-of-town family and nearby relatives more often. That family feeling can grow well beyond your natural kin.

Even if you only end up doing only one of the above actions consistently over the course of a few weeks, you will slowly find that it starts having a positive influence on your thoughts and feelings.

Blessings 'til next time
Perry :-)



Perry Bray



Members News...



Support groups:

Make connections, get help.

This was in one of our issues in about 2015 and we decided maybe it was time to re-submit it.

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

Support groups bring together people facing similar issues, whether that's illness, relationship problems or major life changes.

Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same situation. While not everyone wants or needs support beyond that offered by family and friends, you may find it helpful to turn to others outside your immediate circle

A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges. A support group shouldn't replace your standard medical care, but it can be a valuable resource to help you cope.

Understanding support groups

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

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

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

Support groups also come in a variety of formats, including in person, on the Internet or by telephone. They may be led by professional facilitators — such as a nurse, social worker or psychologist — or by group members. Some groups are educational and structured. For example, the group leader may invite a doctor,

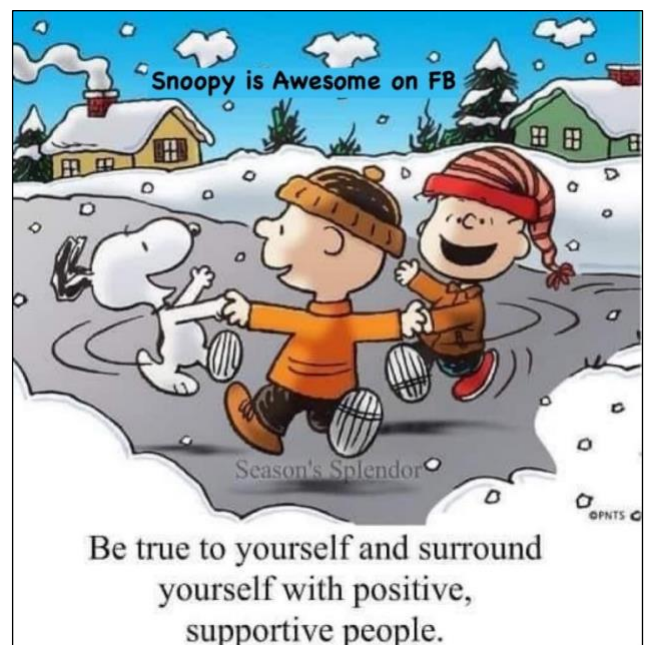
psychologist, nurse or social worker to talk about a topic related to the group's needs. Other support groups emphasize emotional support and shared experiences.

Benefits of support groups

Regardless of format, in a support group, you'll find people with problems similar to yours. Members of a support group usually share their personal experiences and offer one another emotional comfort and moral support. They may also offer practical advice and tips to help you cope with your situation.

Benefits of participating in support groups may include:

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



Members News continued..



Southland Scleroderma Group

It was a wonderful lunch get together at Croydon Lodge in Gore on Sunday 30th June, so much talking went on. We arrived slightly early to witness Jenny whipping up the Scleroderma banner, it was an amazingly easy operation and it looked superb.

Jenny had taken the time on her journey to visit Betty who would have loved to be with us but was unable to on the day. Thank you so much Jenny, you are a gem.

Thanks so much to those from Invercargill who made the journey to Gore, (as one did admit it was also a good opportunity to catch up with friend in Gore afterwards) and thanks to our Gore people for being so welcoming.

It was a delight to meet Monique and her Mum Chantelle, it was a bittersweet occasion, the bitter part is that Monique is under 25 and not only dealing with Scleroderma but other autoimmune problems. The sweet part was that she is dealing with this dreadful situation with fortitude, courage. We do hope to meet up with Monique and Chantelle in the future

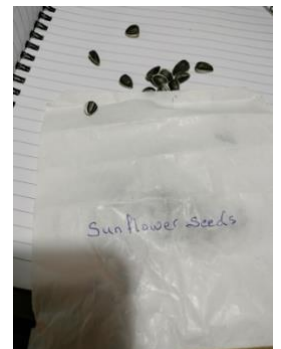
Thanks to Jenny for organising us so well.
Heather Milligan

Our second catch up between newsletters! Southland Lunch, 8th September.

Thank you Jenny, for organising this occasion. So lovely to see members of the Southland group with lots of catching up.

Betty and her husband Brian had grown sunflowers last year. She then collected and cleaned the seeds to give out to us to grow for the coming growing season. A friend of mine has taken them to her local playgroup, she and the children have planted them in pots to take home and others to grow at the Playgroup centre. I hope there will be photos of 'Betty's sunflowers' in the new year to show you.

Heather Milligan





Hawkes Bay Scleroderma Group

Hi well I guess we are all looking forward to spring. Roll on September. Well our group has grown from just Frances and I to a group of 6. A big thanks to Frances for co-ordinating our new girls. We had a meeting last weekend where we all met up at village cafe at Ahuriri. We all had a coffee and chatted amongst ourselves regarding our various types of scleroderma - it was great. So good to hear other people's stories. We will have another meeting next month not sure where yet. We have had some lovely days in HB reaching 22 and ova. Bit of a shock again to wake up this morning to 1deg. I hope all the girls down south are keeping warm.

On a personal note I am attending a seminar re living with chronic illness. It is really good and helpful - run by DHB and is 8 weeks. Hope all you sclero girls and boys are all well. Roll on summer.



Frances, Lorraine, Di, Diana and Gail



Christchurch Scleroderma Group

The Christchurch group met for a mid-winter lunch in July. It was a nice but a rather small turnout. Thank you to Nicky for taking on the leadership role of the group.



Bay of Plenty Scleroderma Group

Despite meeting in the middle of winter, our last group meetup was a cosy one as we got to sit near the fireplace at Nourish Cafe in Te Puna.

With the smell of coffee and tea wafting through the air, we dove into discussions about our health journey, recent health discoveries, swapping tips on nutrition and self-care routines.

We hadn't seen Jane for so long, and she was working on her book on Helminth Therapy. We were all eager to hear more about her progress.

She told us about the challenges she'd faced and the joys she'd experienced. We offered support and encouragement, and we couldn't wait to read her finished work.

Time flew by, and we left feeling relaxed and connected.

If you would like to join them get in touch with Alumie Nguyen: alumie.uow@gmail.com



Left to right: Barbara H, Jane, Donna and Alumie



New Plymouth Scleroderma Group

The New Plymouth group met recently for a chat and friendship.

If you would like to attend the New Plymouth Support Group please get in contact with

Kelsi Tidswell: kelsitidswell@gmail.com





Wellington / Kapiti and Wairarapa Scleroderma Group

A small gathering attended the meeting on the 20th of July at the Fisherman's Table Restaurant in Paekakariki. This was in part due to the terrible weather we had been experiencing in the days prior, school holidays and a number of people who had other engagements.

For those that attended though it was a great time to touch base and catch up with what we'd each been doing / going through over the past few months. Much discussion was had about making the most of every opportunity to travel and get out and about enjoying the things that bring life and wholeness.

Our next meeting will be at the Chocolate Fish Cafe in Miramar on Saturday 21st of September @ 12:30pm see the advert for more details :-)



Wellington Group at their meeting



Waipa and Waikato Scleroderma Group

Waikato Scleroderma group continue to meet . Please contact Erena Bruce if you wish to join them. How blessed are we to be able to be supported and support each other. We look forward to our next gathering.



Nationwide Online Scleroderma Group

Since the last newsletter we have had two nationwide online support group meetings, the first being an impromptu meeting on World Scleroderma Day. We'd recognised that a number of people with Scleroderma may find themselves isolated at home and would appreciate some screen time with others just to hang out with like-minded people for an hour or so. This gave them an opportunity to chat in a group setting with sojourners up and down the country and offer support to one another. It was well attended and a fun time was had by all.

The second was on the 31st of August and again was well attended with people sharing aspects of their Scleroderma journey with one another, offering support and encouragement especially to those that have been recently diagnosed. With spring literally around the corner we also shared what we were looking forward to, those things in our lives that bring us joy and fulfilment. Getting out and about, feeling the warmth of the sun on our backs was a common feature :-) I'm looking forward to catching up again with you all on the 26th of October, the Zoom link will be sent out via email and posted on Facebook closer to the meeting :-)

Perry



Auckland Scleroderma Group

Helen Parsons continues to host Monday coffee mornings for people with Scleroderma, their friends, and families.

However our numbers remain very small.

Please email Helen Parsons.

helenparsons@artcardsandposters.co.nz

if you have requests or ideas for this group.

We find it friendly and informative. We talk about our travel adventures, our families, our hobbies, and of course the scleroderma medical journey that we are all travelling.

Helen Parsons

HelenParsons@artcardsandposters.co.nz

021 248 3869



Events Happening:

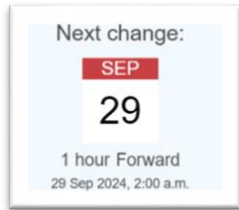


Te Wiki o te Reo Māori (Māori Language Week):

16th – 23rd September 2024

Te Wiki o te Reo Māori is an annual celebration held in the third week of September, and this year, it takes place from

September the 16th through to the 23rd.



Day Light Saving

Saturday 29th September 2024

Don't forget to put your clocks 1 hour forward on Saturday night when you go to bed.

MHAW
Mental Health Awareness Week
23 - 29 SEPTEMBER 2024



Wellington / Kapiti and Wairarapa Scleroderma Support Group:

Saturday 21st September 2024 at 12.30pm



Our next Scleroderma NZ Zoom meeting:

Saturday 26th October 2024 at 1.30pm



Scleroderma Victoria:

Saturday 9th November 2024



Wellington / Kapiti and Wairarapa Scleroderma Support Group:

September 2024– November 2024

All Welcome

Co leaders contact details:

Perry Bray: perry.bray@salvationarmy.org.nz

Cushla Marsters: cushla.marsters@solnetsolutions.co.nz

Tina Mclean: altinamclean@xtra.co.nz

Date & Time	Venue	Address
Saturday 21 st September 2024 12.30pm	Chocolate Fish Cafe	100 Shelly Bay Road, Miramar
Saturday 23 rd November 2024 12.30pm	The Farm Cafe & Bar - Boulcott's Farm Heritage Golf Club	33 Military Road, Boulcott, Lower Hutt



Christchurch Scleroderma Support Group:

September 2024 – November 2024

All Welcome

We welcome any new members to come along.

Please contact:

Nicky Moore: nicky.moore@xtra.co.nz

Date	Venue and Time	Address
21st September 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch
23rd November 2024	Burwood Hospital Travis Courtyard Café Saturday 2pm – 4pm	300 Burwood Road, Burwood, Christchurch



Give a little: Scleroderma NZ Inc.

From [Scleroderma New Zealand Incorporated](#) - Givealittle

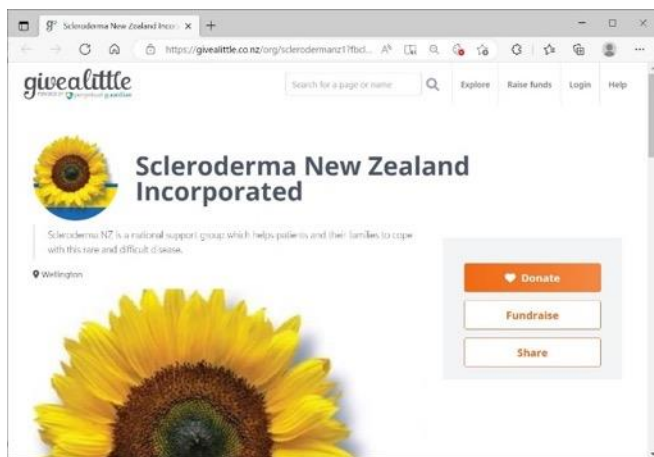


Scleroderma New Zealand Incorporated

Scleroderma NZ is a national support group which helps patients and their families to cope with this rare and difficult disease.

An example of what our give a little website page is shown below:

[Scleroderma New Zealand Incorporated - Givealittle](#)



Our give a little URL link address is shown below: -

<https://givealittle.co.nz/org/sclerodermanz1?fbclid=IwAR29Znk701JSOwf9n0Ew-063nj0FrySOCpV44mBCpIPhtXV7Uff9KIAAnAzM>

If you are donating or you are circulating the givealittle link, please make sure you use the above address link, thank you.

Many General Practitioners have not had experience with this disease and Scleroderma NZ aims to help promote knowledge among our medical professionals and patients, by supplying them with educational booklets and hospital checklists for special requirements.

The purposes of Scleroderma NZ are to support, friendship, education, awareness, advocacy, lobbying, prevention, research and assistance with health care for people, their families and communities with Scleroderma (Systemic Sclerosis) and Undifferentiated Connective Tissue Disease

Jokes from Ian McLean

How does a tree get onto Google ?

- It logs on..

Do you know that a frog can jump higher then the Eiffel Tower ?

-that's because the Eiffel Tower cannot jump....

What kind of cheese do you use to get a bear down from a tree ?

- Camambert...

What did the block of cheese say when it looked in the mirror ?

- Haloumi....

If two vegans are fighting is it still considered a beef ?

What is green and fuzzy, has four legs and if it fell out of a tree it would kill you ? - A pool table.

What's blue and is not very heavy ?

- light blue...

Did you hear the rumour about the butter ?

- never mind I'm not going to spread it.

Yesterday I purchased a world map - I gave my wife a dart and said "where ever it lands we'll go"

- turns out we are spending 3 weeks behind the fridge.

The son walks in and asks "Hey Dad did you get a haircut ?"

-The Dad says "No, I got them ALL cut"...

The jokes above were told to me by my son Ian, who is now a boisterous happy, fun loving 13 year old. For those who haven't met Ian, he is our very special scleroderma baby, as when I was initially diagnosed with Scleroderma in 2004, I was advised that we shouldn't think about having children. My husband Alastair and I decided to ignore the advice and at the start of 2010, and with proper consultation from my medical team, I stopped taking methotrexate (DMARD drug) and we tried for a baby. By the end of 2010 I was lucky to conceive and by June 2011 Ian was delivered by caesarean at 29 weeks. Ian spent his first 9 weeks at Wellington Hospital in the care of the NICU team and by the time he was 38 weeks old, we were able to take him home.

Warmest regards,

Tina



Ian in NICU-2011



Ian now-2024



Group Meetings Dates: Regional

Wellington / Kapiti and Wairarapa support group meets:

Venue: *Chocolate Fish Cafe*

100 Shelly Bay Road, Miramar

Time: Saturday 21st September 2024 at 12.30pm

For any enquiries please contact Cushla:

cushla.marsters@solnet.co.nz

or Perry: perry.bray@salvationarmy.org.nz

Christchurch support group meets:

Venue: *Burwood Hospital, Travis Courtyard Café, 300*

Burwood Road, Burwood, Christchurch

21st September 2024, Saturday 2pm-4pm

(Please RSVP to Nicky ASAP so she can book for the correct number)

Dates: 23rd November 2024

Time: Saturdays 2 - 4pm.

We welcome any new members to come along.

Please contact **Nicky Moore** if you would like to join in:

nicky.moore@xtra.co.nz Phone: [021 110 6123](tel:0211106123)

Southland support group meets:

Venue: *Croydon Lodge, Gore*

Sunday November 24th, 12pm

Please contact **Heather** if you wish to join us.

milliganseeds@xtra.co.nz

Waikato/Waipā support group meets:

Venue: *Circus Eatery, 29 Pengover Avenue, Cambridge Park, Cambridge*

Sunday, 29th September 2024, 10.30am

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

Erena Bruce, Mobile: **021 186 9680**

Rachel Burgoyne, Mobile: **027 3661881**

Palmerston North support group:

See Wellington Support group.

Otago support group:

Please contact **Gay** if you wish to join us.

gaymeddings@gmail.com

Waimate/Oamaru support group:

We have ladies meeting up in these areas so if you are interested in joining them please get in touch with

Helene Sunitsch at: hkjsunitsch@gmail.com

Auckland support group:

Venue: *Dailey Bread, Kings Garden Centre, 11 Porana road, Takapuna,, Auckland*

Time: Monday 21st October, 10am

A reminder email to be sent out one week prior to each meeting to all in the Auckland area. If you would like added to this email list contact either Helen.

For any enquires please contact either:-

Helen Parsons: 021 248 3869

HelenParsons@artcardsandposters.co.nz

New Plymouth support group:

If you would like to attend the New Plymouth Support Group please get in contact with **Kelsi Tidswell:**

kelsitidswell@gmail.com

Blenheim/Nelson support group:

Jen Soane is organising the Blenheim/Nelson support group so if you would like to attend please get in touch with Jen: jennasoane@gmail.com

Hawkes Bay support group meets:

Venue: *Figgery Café, 205 Napier Road, Havelock North*

21 September 2024, 11am

If you would like to join in with the Hawkes Bay Group, get in touch with Gail.

Gail Neilson: gail_neilson@hotmail.com

Bay of Plenty support group meets:

Venue: *Café Nineteen, KatiKati Golf Club*

Time: 5 October 2024, at 11.00 am

Come join us for more informative discussions and good company! Can't wait to see you there!

Please contact one of us for information.

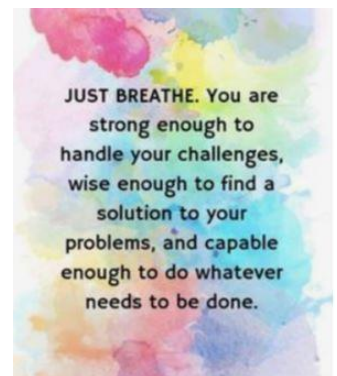
Jane: janepuckey99@gmail.com

Mary:

marybestrd3@gmail.com

Alumie:

alumie.uow@gmail.com





Welcome to Scleroderma New Zealand Inc.

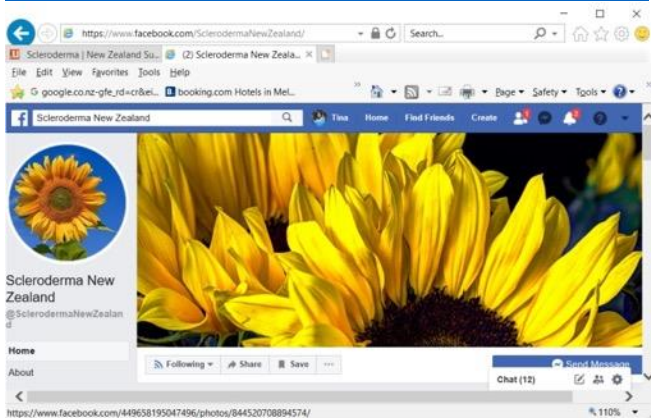
To all our new members, who have recently joined us – Welcome....

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.

Link to our Website address below: - <http://scleroderma.org.nz/>



Link to our Scleroderma NZ Facebook page: - <https://www.facebook.com/SclerodermaNewZealand/>



Link to our Auckland Facebook page: - <https://www.facebook.com/groups/sclero.ak/>



Scleroderma New Zealand

President: Jenny Andrews
jennyred@xtra.co.nz

Vice President: Tina McLean
altinamclean@xtra.co.nz

Secretary: Jane Sainsbury
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

Committee Members:

Linda Bell, Erena Bruce, Cushla Marsters, Dianne Purdie, Heather Milligan, Alumie Nguyen, Frances Tod, Rachel Burgoyne, Helen Parsons, Perry Bray and Helene Sunitsch

Contacts:

Find a Scleroderma a Support Group near You:

Auckland: Helen Parsons, Email: helenparsons@artcardsandposters.co.nz

Bay of Plenty: Alumie Nguyen, Email: alumie.uow@gmail.com

Waikato/Waipā: Rachel Burgoyne, Email: rachieb1981@gmail.com
Erena Bruce, Email: glenanderena@xtra.co.nz

Hawkes Bay: Gail Neilson, Email: neilson_gail@hotmail.co.nz

New Plymouth: Kelsi Tidswell, Email: kelsitidswell@gmail.com

Wellington: Cushla Marsters
cushla.marsters@solnetsolutions.co.nz
Perry Bray
perry.bray@salvationarmy.org.nz

Christchurch: Nicky Moore, Email: Nicky.moore@xtra.co.nz

Blenheim/Nelson: Jen Soane, Email: jennasoane@gmail.com

Waimate/Oamaru: Helene Sunitsch, Email: hksunitsch@gmail.com
Gay Meddings, Email: gaymeddings@gmail.com

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

Southland:

