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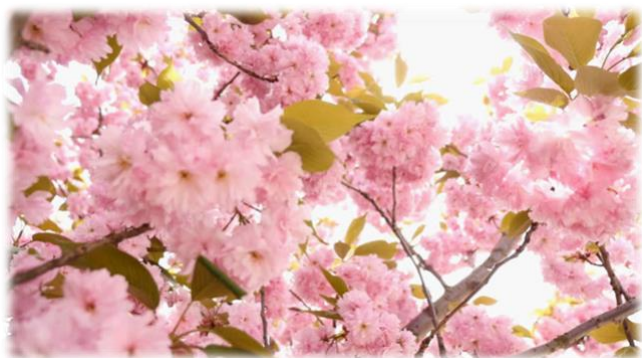
Scleroderma

New Zealand support group

Spring 2020

Greetings to you all.

Welcome to the Spring edition of our Scleroderma Newsletter. We hope everyone is well.



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.

We have a Memorial to John Spavin, very sad news of John passing. John has been very dedicated and kind to Scleroderma New Zealand over the past eleven Years. He has worked continuously until recently on our website and also with his lovely wife Barbara for at least ten years on our national newsletter.

He has always been cheerful and thoughtful to us all throughout the country and worked tirelessly to support all of us and always with a smile and ready to do his best to fly the flag for Scleroderma New Zealand. John will be sadly missed by us all.

Our thoughts are with Barbara and her children Dan and Clare and family over this very sad difficult time.

Take Care with Sincere Wishes from,

Dianne and Gordon and All of us at Scleroderma New Zealand

We have information on living with Scleroderma, How to create a Self-Care Routine. We see new promotional material kindly created and gifted to us from Carolyn Barkhausen. Thank you Carolyn. We hear stories from Dianne regarding the Hutt Valley Horticultural Society Spring Show, Tina shares about her cats, Rosie and Ginger. We have two new sections called; Book Club, and Today's Recipes. Members news and upcoming events of what is happening around the country. Members are encouraged to submit something to us to keep the newsletter fresh and interesting.



Presidents Report:

September 2020



Presidents column
September 2020

Welcome to Spring!

I hope that you have all been keeping warm and well over this relatively mild winter.

On a very sad note we lost John Spavin due to a serious illness a few weeks ago. You will see his

memorial later in the newsletter, our thoughts and care go out to Barbara and family over this difficult time.

Recently with the great help from Carolyn Barkhausen, Scleroderma NZ now has some pens with our name on them to give out to members at seminars and hospitals. Carolyn also organised some great seminar folders, bookmarks, cards, and magnetic notepads for our seminars as well. This has been a huge boost to us, and I would like to send a huge thanks to Carolyn, for her dedication and thoughtfulness for organising and donating most of these goods. We are all very much appreciative.

It has been a very quiet winter for most of our groups over winter, especially with the covid-19 restrictions. The Wellington group has not been meeting due to the restrictions, but we did have a National Zoom Meeting on the 13th of August in place of our usual meeting. There were a few people from around the country that met up online from Hamilton, Auckland, Invercargill, Wellington, and the Kapiti Coast so that was terrific. Linda Bell the leader of the Hamilton group and Beth Richards the leader of the Nelson group have been meeting up, which has been nice for their members.

We hope to be running monthly Scleroderma NZ zoom meetings for everyone around NZ to meet at the same time. Dates will be noted later in the Newsletter.

Erena Bruce from Cambridge, is looking at setting up a new Scleroderma NZ support group in Cambridge which is terrific, more about this later in the newsletter.

The Invercargill and Hamilton seminars have been postponed due to the serious covid-19 issues. We hope to have our seminars back up and running when we have a vaccine. It is too difficult to organise these events when we don't know when there will be another outbreak.

We have a few people attending the last of the SPIN leadership program for 2020, we have had a good turn out of participants.

A few of us are still doing our fortnightly – monthly COVID-19 SPIN Chat surveys.

Next week I will be undergoing an interview with the SPIN team in Canada, as part of their ongoing research project into the effects of their SPIN Chat group for people with Scleroderma during COVID-19.

I am thinking that I would like to do another survey on the health of our members like we did a few years ago, and put in a few questions about how we have all coped with covid-19 so watch out for this space.

My appreciation goes out to Tina and Jenny for their fantastic newsletters, I have had lots of positive feedback, they both make a terrific team.

A huge thanks to Gordon as he has taken over as website master, so if you would like anything put up there please contact him on:

gordon.purdie@xtra.co.nz

Until then you all take care and keep well.

Kind Regards

Dianne and Gordon



Memorial for John Spavin

It is with great sadness that we bring the news of John Spavin passing on the 31st August 2020.



John Christie Spavin



Died peacefully on Monday, 31 August 2020, aged 69 years. Much loved husband to Barbara. Loved father to Clare, and Daniel. Loved brother to Kathleen. Loved father-in-law to Michal, and Andrew. A loved granddad to Emma, and Tim. A treasured friend to many. In lieu of flowers, the family suggests donations be made to Te Omanga Hospice in John's name and may be left at the Church.

A funeral service was held for John at the Church of St Francis Xavier, 152 Stokes Valley Road, Stokes Valley, on Wednesday, 16 September, commencing at 1.30pm.

For those who cannot make the service, please email info@ninness.co.nz for the livestream link. Messages for "The Spavin family" can be sent c/- PO Box 50-347, Porirua 5240.



Scleroderma New Zealand Newsletter Editor and Webmaster

John had been fighting a serious illness for approximately the last 15 months and he will be sadly missed by us all especially in the Wellington, Palmerston North and Southland regions.

John had been our Newsletter Editor along with his wife Barbara, for a good ten years until a year ago. John was also our Webmaster who developed our Web site a good ten years ago until a few months ago.

John was a brilliant journalist, and wrote with a quick articulate wit, and we were very lucky to have him. John has worked for many community groups; he has been a good man to many!

John will be remembered for his unbreakable dedication to Scleroderma NZ and to his wife Barbara who has Scleroderma. All his beautiful work was much appreciated and valued over those years, and he will be remembered for his pleasant, happy helpful nature, he was always keen to help in any way he could for Scleroderma NZ and certainly flew our flag far and wide. John will be sadly missed by us all.

Our Kindest thoughts are with Barbara and family.

Dianne Purdie



Living with Scleroderma...

Living with scleroderma can be a challenge at first but we have put together some tips and ideas that will help you get started. It is important to point out that most of the tips included here have come from people with scleroderma. They will have experienced many different symptoms- some you may know about but others which may not be relevant to you. If you are unsure about anything you see, please check with your doctor to make sure that it is suitable for you to try. Above all, use your common sense.

Firstly, it is worth mentioning the initial shock many people may initially have on diagnosis, when you first become aware of the implications of having scleroderma. It is a natural reaction to the discovery that you have an incurable disease, its potential impact on your appearance and life. And of course, the fear of what might be to come. This is all completely normal!

SYMPTOMS WE MAY SHARE

- One of the things that all people with scleroderma share is the need to protect their largest organ: the skin. The simple advice there is to moisturise, moisturise, moisturise.
- People with systemic scleroderma may also share poor circulation and suffer from secondary Raynaud's phenomenon and as such they share the need to stay warm.
- Some may share poor mobility.
- Most people will share pain at some time during the disease but for some this will be chronic.
- Many others will have a problem with their bowel, their oesophagus, and other parts of their gut.
- Many people will also share other medical problems.

WHAT ABOUT THE HANDS?



It is important to keep your hands warm, however, you should be careful not to touch radiators or hot water when your

hands are cold as if they are numb and you have lost feeling in them, you may burn yourself. Many people with scleroderma become used to wearing gloves both inside and outside.

Find a glove made of a material which suits whatever you are doing. They could be woollen, cotton, rubber, or contain silver. Make sure that you have gloves that are appropriate for cleaning and cooking as well as gloves for protecting your hands from the cold. Gloves are also useful for protecting your hands from trauma; try to avoid doing things that might break your skin or find a way to protect your hands.

Hand warmers are very useful. There are a huge variety on the market and while we do not recommend any particular one, try out different ones and find one that suits you.

If you are carrying shopping, try to carry shopping bags on your arms and not with your fingers to avoid restricting circulation to your fingers. Alternatively, there are plastic carrier bag holders available on the market.

"Again, moisturise, moisturise, moisturise!"

Also think about hand wax.

YOUR FEET

Moisturising is also very good for your feet. If you cannot reach your feet with ease, you could put some moisturiser into a bag and then put your feet inside the bag. It is also important to keep your feet warm. You can turn socks inside out so that seams will not exacerbate poor circulation, and it is possible to get aids to help with putting on socks and tights. It is important that you maintain good podiatry care and you should be able to get a referral to an NHS podiatrist. Insoles may also help, although there is no clinical evidence to support this as yet.



Living with Scleroderma *continued*

YOUR HEAD AND FACE

Learn to love a hoodie, especially on yourself. It is important to cover up, especially in winter so wear hoodies, hats and scarves. "Wear as many hats and scarves as necessary to cover every open bit of skin in winter". Again, protect your skin with moisturiser- this applies to the whole body and also remember to protect your lips with lip balm or lip gloss. If your nose feels the cold, make sure it is covered with a scarf.



You can hide telangiectasia with foundation and make-up and there is plenty to choose from on the market. Also, laser treatment

may be available with a referral from your consultant. Good dental hygiene and mouth care is essential and it may be worth investing in an electric toothbrush. If you suffer from receding gums, make sure that you always carry some dental floss or toothpicks.

BODY AND MOBILITY

You need to look after your body. Apart from keeping warm and moisturising, think about exercise and physiotherapy. It is also important that you get enough sleep.

Also, make sure that you pace yourself. If you know that you are going to be busy, make sure that you make time both before and after to recharge your body. Most of all, listen to your body and take note.

PERSONAL HYGIENE/BATHING



If you have limited mobility, this can impact on your personal hygiene regime, although there are many products that you

can now get to help you out. Getting in and out of the bath can sometimes be tough so it can be worth getting a bath chair or blow up bag to help out. A shower chair can also be helpful. A long-handled brush or sponge can also help.

It is worth using emollients if soap is too drying to your skin. For maintaining good oral hygiene, it is useful to use an electric toothbrush. You might find that a referral to an occupational therapist could help you.

GUT AND BOWELS

Reflux can be a real problem for people with scleroderma. A good way to help reduce reflux problems at night is to place some blocks underneath the feet at the head of your bed so that the upper half of your body is elevated slightly above the lower half of your body, which helps reduce reflux that comes when lying down. You can also help control reflux by eating little and often and it also may help to avoid eating late at night. It is wise to learn what foods may affect you and then to only have them as a treat now and then. If incontinence is a problem for you, it is worth making sure that you are prepared with a change of underwear and some pads.

EATING AND FOOD PREPARATION

Remember to eat slowly and chew thoroughly. Also, cut your food into small pieces and ask for help if you need it. There are many more aids available today including cutlery with thicker handles.

ATTITUDE

Last but by no means least comes attitude. Your life with scleroderma will very much depend on your attitude to it! So, remember:

- Don't beat yourself up if you have a bad day.
- Positive thinking is essential, although we know sometimes it is not always possible.
- The importance of communication with family, friends and colleagues.
- Get out and about in the fresh air if you can and it's not too cold.

Source:

<http://www.sclerodermasociety.co.uk/living-with-scleroderma.html>



Self-Care:

What Is Self-Care? And the Most Practical, Enjoyable Ways to Weave It Into Your Life

The phrase “**self-care**” is a popular one, and conjures up images of luxurious bubble baths with a glass of wine or hour-long meditation sessions. Self-care has long been misunderstood in many ways, perhaps a mantra reserved for yoga-doers, an indulgent brushing aside of responsibilities or as therapy only when feelings of stress, depression and anxiety are at their worst.

But in recent years, the concept of self-care has become so universal that the World Health Organization now officially recognizes it as an essential ability to care for ourselves, our families and our communities.

What is self-care?

Self-care is the practice of protecting and improving your physical and mental health. The scope of self-care is broad, but the key word in its definition is practice. So, it includes anything you do on a regular basis, with or without the direct support of a healthcare professional, to keep a healthy, balanced lifestyle. Examples include:

- Maintaining good personal hygiene
- Eating a nutritious diet
- Getting enough hours of sleep, and ensuring that your sleep is actually restful and restorative
- Engaging your body in a mix of exercise and relaxing activities
- Maintaining financial wellness and security
- Nurturing feeling of self-reliance, confidence and empowerment
- Taking care of your spiritual needs
- Participating in your community
- Following a treatment plan prescribed by your doctor
- Tending to your relationships and building strong networks of social support

Why is self-care important?

The clear intention of self-care is to help you live a longer, happier life. But if that is too abstract, consider these very real outcomes of practicing self-care.

Physical and mental benefits:

Any time that you choose to take a walk, snack on fruits and veggies, go to bed a little earlier or treat your skin to a nourishing product—these small acts of self-care add up to huge benefits.

Simple lifestyle choices, including regular exercise and a nutritious diet, have been proven to drastically reduce the risk of chronic diseases, including heart disease, diabetes and some types of cancer. Even applying sunscreen every morning is a form of self-care, as you are taking the time to protect your skin from the sun’s damaging effects.

Feeling stressed out often? Although it can be difficult to keep stress at bay when there are so many daily demands to meet, the cost of not doing so is high. Chronic stress causes not only bothersome headaches and heartburn, but is also shown to weaken your immune system, accelerate the signs of ageing, and worsen conditions like depression, diabetes, heart disease and asthma.

Sometimes stress, anxiety and other negative emotions are unavoidable. Studies show that people who experience frequently high levels of emotional distress often rely on harmful coping mechanisms, including smoking, drinking alcohol and eating unhealthy foods. But practicing self-care can help you manage these feelings in healthy ways, both in the heat of the moment (for instance, anxiety attacks) and for the long-term goal of resiliency. Plus, taking care of your mental and emotional health is associated with higher overall productivity and stronger relationships.

Related: Instant Mood Boosters (in next newsletter)

Source:

<https://parade.com/1039023/allisonscerbomusan te/w hat-is-self-care/>



How to create a Self-Care Routine:

Self-care is like any other healthy habit—if you want to reap the full benefits, you have to consistently set aside time and attention for it. Here are four tips to create a self-care routine that works for you.

1. Plan it like any other appointment.

If you're someone who struggles with self-accountability, it's easy to let self-care fall by the wayside when others' needs or other commitments arise. Put your self-care activity in your calendar, set yourself reminders and treat it as an equally important part of your daily or weekly schedule. Even busy moms can practice self-care when it's integrated into their routine.

2. Be flexible and keep it simple.

If you make your self-care ritual complicated or inconvenient, you're not likely to stick to it. Couldn't get to the yoga studio this week? Instead of skipping it altogether, find a quiet space at home, light a favourite scented candle and do some light stretching on your own or practice mindfulness with an app or guiding video.

3. Do something you actually enjoy.

Don't force yourself to maintain a hobby because you think it's what you're supposed to be doing. Maybe meditation isn't your thing. That's OK. Be honest with yourself about the things that make you feel calm, happy and energized. No judgment here.

4. Don't feel guilty about your self-care time.

You can't effectively care for others when you are not caring for yourself.

Related: [How to Meditate](#)

Self-care activity ideas

Practicing yoga, treating yourself to a spa day, and cosying up with a cup of tea and a good book are just a few of the hundreds of self-care activities you can try right now. Here are 13 unique self-care ideas you may not have thought of:

1. Dabble in the kitchen with a new or tried-and-true recipe. Cooking is therapeutic! Time spent in the kitchen is linked to more intuitive eating habits, making healthier food choices, and improving mood and feelings of self-reliance.

2. Or, try a meal-kit service to take the pressure off of planning fresh, healthy meals this week. Maybe it will inspire you to try new flavours, and you can use that prep time doing something else you enjoy.

3. Post self-love quotes somewhere you'll see them every day, like on your phone or your mirror. Self-affirmation helps many people overcome negative thoughts.

4. Try mindfulness, a practice of focused breathing and observing your thoughts and senses. The best part? You can do it anywhere, and even a few minutes can recharge you.

5. Learn how to say "no" before you become overwhelmed. It's also OK to cancel plans and step away from people and tasks that ask too much of you.

6. Try a new approach to journaling—make it fun and colourful!

7. Talk to a trusted friend or family member about what stresses you out, but remember you can always talk to a mental health professional when you need a little extra help.

8. Detoxify your social media by unfollowing anything (or anyone) that feeds your negative thoughts, including FOMO and poor body image.

9. Bugged down by mundane tasks, like chores and paying bills? Stop procrastinating and tackle what you can in what happiness expert Gretchen Rubin calls a "Power Hour."

10. Make your self-care social. Book club? Wine club? Whatever you want to call it, a self-care club creates built-in time and accountability to do what makes you happy.

11. Give your Netflix binge a break and try listening to a podcast that discusses self-care, self-help and other mental health topics.

12. Plant a garden, even if it's just a mini herb planter on your apartment windowsill. Science shows that gardening has many therapeutic benefits, including lowering depression and anxiety and increasing attention.

13. Power down all electronic devices at least an hour before bedtime. Their blue light is proven to keep your brain alert longer, disrupting your sleep, and may be contributing to headaches and eye strain (plus, the midnight shopping or endless Insta scroll are probably not good for you either)



Promotional Scleroderma Material:

Donated from Carolyn Barkhausen

A huge Thank you to Carolyn Barkhausen for gifting Scleroderma New Zealand with some professional stationary and organising some pens for Scleroderma New Zealand, for our members at regional and national seminars.



The gifts included as seen here, conference folders, magnetic shopping lists, book marks, cards and all with our logo beautifully presented .



The pens have Scleroderma New Zealand written on them, which are light and are easy to use for people with troubled hands.

We really appreciate the effort and kindness that Carolyn has shown to people with Scleroderma here in New Zealand.

Thank you Carolyn :-)

Dianne Purdie

Information Wanted:

Compression Gloves (full fingered)

Leonie has been in touch and is on the hunt for **full fingered compression gloves**. Does anyone have any recommendations for her. She would love some feedback on what has worked.



If you have any information for Leonie, please email me on: jennyred@xtra.co.nz for me to pass on to her and we will publish in the next newsletter.

Joke of the day:



Members Stories:

Chris Carlyon shares her experience at the Wellington Exhibition...

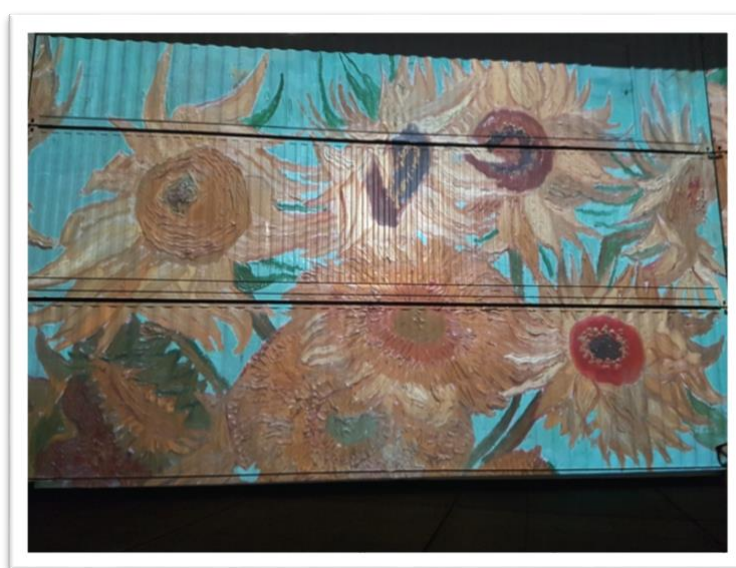
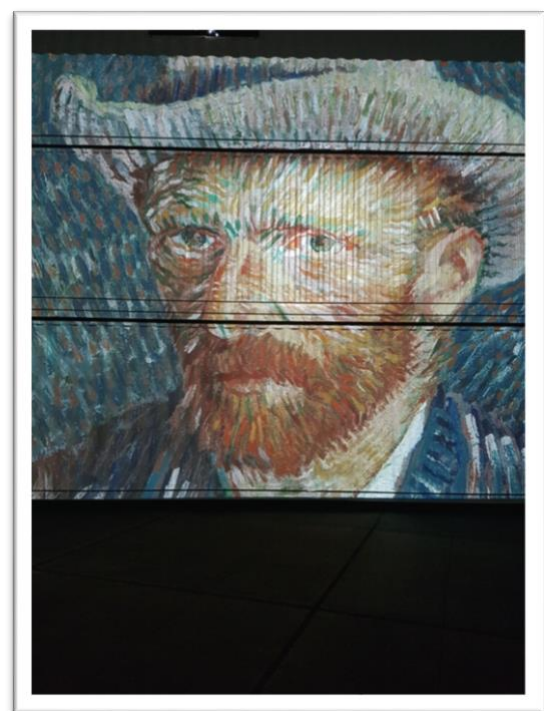
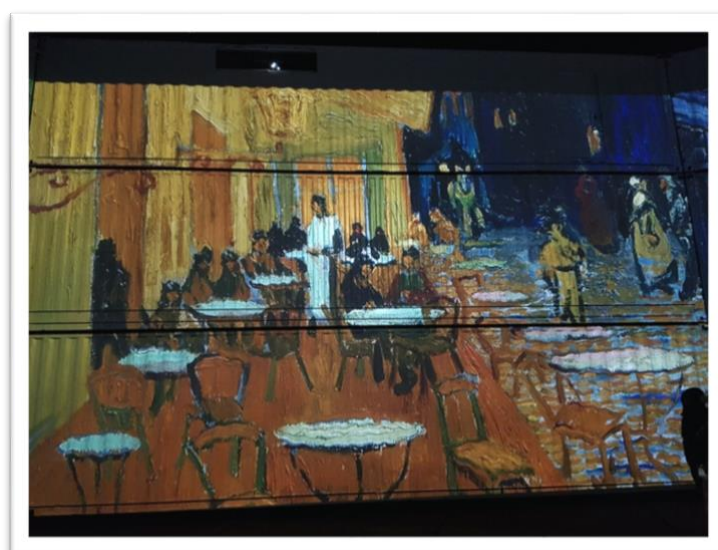
Just thought I'd let you know I had a great experience Sunday evening, interacting with art at the Van Gogh digital night show Wellington exhibition. It was really impressive.

The images were projected onto shipping containers and we were immersed in a vibrant symphony of light, colour and sound.

All the bold colour and expressive brushstrokes certainly left me wanting to get the oil paints out and create.

I recommend the experience if you are passing through Wellington before the end of October. Here are some pics.

Cheers Chris



Carolyn Barkhausen – Tragic Doll

Carolyn watched a section of Ripley's Believe It or Not about The Tragic Doll. Have you seen it? Terrible to get scleroderma at any age, but at 9 years old ... Have a look on the internet.

At just nine-years-old Shirley Alvarez was diagnosed with systemic scleroderma, an autoimmune disease which hardens soft tissue throughout the body and can affect the entire body, including blood vessels.

Within a matter of months, Shirley went from using a walker to being a full-time wheelchair user and had to quickly adapt to her new life.

Shirley, from Queens, New York, created a new persona called the 'Tragic Doll' to express how it feels to live with scleroderma.

Shirley, now 27, told Barcroft TV: "The 'tragic doll', is what I call myself. That is my persona, that is the way that I express myself.

"I always felt like I was trapped, my soul was trapped in a foreign body and so I thought a doll was the best concept of expressing how I feel living with scleroderma. "I might be a little fragile looking, I might have porcelain-like skin but I feel like there's this immense strength within myself and I want to try and project that.

"I think my lowest point in life was probably when I was a child, I think, as soon as I was diagnosed with scleroderma.

"The progression was so fast it happened in a matter of weeks and it was very traumatising going from a child that was independent and active and dancing, to all of a sudden needing so much help getting dressed in the morning to feeding yourself without the ability to really dance anymore.

"It's a very complex disease and an immune disease that affects the connective tissues and it makes the skin very hard like stone from the inside out.

"I went from walking using a walker and then in a couple of months using a wheelchair."

Shirley also has Raynaud's syndrome, a medical condition where the arteries spasm and reduce blood flow to the extremities, which often comes hand in hand with scleroderma.

After struggling to come to terms with her condition, Shirley decided to reshape her mentality and make the most out of every day.

She said: "I remember sitting in a chair, I was very exhausted, and I looked at myself in front of a mirror and I asked why me? Like, why is this happening? What

did I do to deserve this? And I just felt pity for myself, after a few minutes I was like you know what I'm gonna snap out of it.

"From that day forward I changed my mentality and I just started to think positively and just go with it and make the most out of it every day, which is what I have done until today."

Shirley discovered a passion for music, art and fashion which helped her to express her true self. She said: "When I was about 16-years-old, I discovered goth. It matched my style, matched my personality. I look at fashion as an art form, I like to express myself with fashion. It taught me a lot with my confidence.

"I didn't think I could dance or move that same way again, but I decided to embrace my limitations, even use my chair as a prop. I began dancing with my sister without any fear."

Shirley's sister Tiffany has been by her side every step of the way.

Tiffany: "We were always together. She's always been dancing, always been a ball of energy. She's the reason my life is so interesting, she's the reason I love to dance, she's the reason I'm into fashion.

"She influences me a lot with all these things, she is a wild thing, she is rebellious, she is an amazing person."

Shirley also created the concept of herself as the 'Tragic Doll' to give herself a persona to be creative with.

She said: "I think I've gone through the worst in my life, anything else is just microscopic. I think when you have pain it's only going to build character, build your strength.

"Life will never be perfect, it will never be a perfect path. Over the years, I think the tragic doll helped me find a way to be more confident in my own skin and accepting that there is alternative beauty.

"Showing people that there's a different kind of beauty and seeing beyond that."



Shirley Alvarez

Source: <http://www.barcroft.tv/the-tragic-doll-diffuse-scleroderma-autoimmune-condition-skin-hardening-shirley-alvarez>



Hutt Valley Horticultural Society Spring Show

On the 12th and 13th of September, I was involved in the organisation of the Hutt Valley Horticultural Show.

It was held at the new Events centre in central Lower Hutt. We featured the Local Bonsai 40th Anniversary where they had talks and workshops along with many interesting Bonsai plants for display.

The Horticultural Society featured lots of Daffodils and other spring flowing plants. we were very lucky to have one of the growers from Otaki supply us with many unusual daffodils for display too.

We had some great plant stalls selling super plants and craft and a children's activity table also to make it an interesting show to attend. It was the only horticultural show that managed to hold a show this year, it was a big treat for the community and we were lucky that a good number of them came along.

Having Scleroderma ensured, that I stayed well out the back away from the public with the concern of covid-19, so I spent my time writing up prize cards for the winners.

In November we will be holding the Summer Show featuring the Roses, Cactus and Succulents. It is good to have something to be involved in out in the community to spread the cheer of the power of beautiful plants.

Dianne



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.



Ian asleep in my arms when he was sick - Rosie insisting on taking her usual spot on my lap.

My husband Alastair never liked cats, and I'm a dog person, so when our son, Ian asked for a pet, we were a bit unsure. I always had dogs when I was growing up, so naturally I wanted a dog, but Alastair wasn't keen on a dog, as all he could see was more work for him as he knew Ian and I wouldn't be able to walk it.

Turn the clock back to August 2004, I was diagnosed with

Scleroderma and I was extremely sick. I had no energy and I was in constant pain. I spent most of my time in bed sleeping and doing a few things before getting tired and needing to rest. At that time, we had a 10 year old German Shepard we called Major. Major understood that I was sick, and spent all his time by my bedside. He was a very gentle dog, but very protective. Alastair had to do all the things that Major required such as walking and feeding him, before leaving for work and than again when he got home. So, when Ian asked us if he could have a pet, there was a lot of resistance.

After constant requests, pleas and numerous trips to the SPCA checking out all the cute little animals, we managed to talk Alastair into letting us adopt a little female kitten we called Rosie. Rosie is a lovely grey tortoiseshell kitten who is fiesty and independent. She settled well into our home but wasn't at all cuddly or affectionate. We managed to successfully look after Rosie, and after a couple of years we decided we would try and adopt another cat, as Ian wanted a male Ginger kitten. Ian's reason was that, Rosie was not his cat, as she only liked me, and would only sit on my lap and no-one else. Alastair thought, that was fine, what was the chance of finding a male, ginger kitten at the cat rescue centre? He hoped it was going to be a slim chance. Well, when we got there, they had quite a few male ginger

kittens. One little shy ginger kitten went up to Ian and that was it. We came home with another kitten. The first night we had Ginger, he hopped onto Alastair's lap and cuddled into his chest and nuzzled his head underneath his chin. For the next few weeks, Ginger liked spending his time sleeping on Alastair's lap. We later realised it is because Ginger didn't like my perfume. It's quite funny, for someone who didn't like cats, Alastair now has two cats and Ginger has become his favourite.

It's turned out that Ginger is a very affectionate cat and loves lots of cuddles. He will put up with all the cuddling Ian gives him, which suits Ian. You can usually find Ian cuddling with Ginger on the couch. Rosie still remains an aloof cat, and will only sit on my lap when she wants affection. Rosie has taken to sleeping on Ian's bed at



Ian and Ginger chilling

night, or rather Rosie lets Ian sleep in her bed.

We have found it is wonderful to have the two cats and they make a wonderful companion for me when I am at home. They are also lots of fun for Ian. Rosie will be 4 years old and Ginger will be to 2 years old this November.



Ian and Rosie

Take care everyone, looking forward to hearing stories about your pets.

Tina



Recipes:

Readers you are welcome to submit your favourite recipes, ideas, suggestions, hints...



Today's Recipe:

CARAMELIZED CHICKEN WINGS

Ingredients

- 3 lbs chicken wings
- 2 tablespoons olive oil
- 1/2 cup soy sauce
- 2 tablespoons ketchup
- 1 cup honey
- 1 garlic clove, minced, to taste

Full Recipe Here: <http://www.recipeoftoday.com/2016/12/caramelized-chicken-wings.html>



ESSENTIAL OIL PERFUME BLENDS			
Floral	Citrus	Earthy	Spicy
 SWEET ORANGE 5 drops	 LEMON 5 drops	 PATCHOULI 3 drops	 BERGAMOT 5 drops
 LIME PEEL 2 drops	 ROSEMARY 3 drops	 PALMAROSA 3 drops	 CLOVES 1 drop
 JASMINE 2 drops	 NEROLI 2 drops	 VETIVER 1 drop	 SANDALWOOD 4 drops
 VANILLA 2 drops		 CEDARWOOD 4-5 drops	 VANILLA 2 drops

8 BEST DIFFUSER BLENDS

for mamas

WAKE UP

- 4 drops Peppermint
- 4 drops Lemon
- 2 drops Frankincense

WORRY LESS

- 3 drops Patchouli
- 3 drops Bergamot

FOCUS

- 3 drops Rosemary
- 2 drops Lemon
- 1 drop Peppermint

STRESS FREE

- 3 drops Lavender
- 3 drops Lime
- 1 drop Spearmint

PICK ME UP

- 2 drops Wild Orange
- 2 drops Frankincense
- 2 drops Peppermint

FATIGUE FIGHTER

- 3 drops Bergamot
- 2 drops Grapefruit
- 1 drop Peppermint

SLEEPY TIME

- 3 drops Grounding Blend
- 2 drops Restful Blend

RELAX

- 2 drops Frankincense
- 2 drops Lavender



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...

If anyone gets the Entertainment Books go to my Facebook page and where you can get online anywhere in NZ or call in to **Target Hamilton** only to pick a book up. The money raised goes towards **Scleroderma Waikato** funds to help with the cost of Seminars.

LINDA BELL
SCLERODERMA WAIKATO

Nelson Scleroderma Group

Beth Richards ...

Hi to all of our Scleroderma friends around NZ. We are having some stunning weather in Nelson this spring. It certainly encourages you to get out in the garden or go for a bike ride and walk.

I'm going for long rides on my Silverado mobility scooter most fine warm days. Great for your well-being and happiness. Fresh air is so good for all of us.

Our group of 4 ladies have met up once over the level 2, but health issues or family commitments have meant that we haven't seen each other for a couple of months. I'm sure we will catch up soon.

We email and text regularly so that keeps us in touch to support each other.

We really enjoy each other's company immensely. Our latest member Jenna has been to meet us all at the Wooden Spoon cafe in Richmond. She is very friendly and bubbly. We all got on so well together. I forgot to take a photo, but will remember next time.

I'm attaching a photo of my 2 granddaughter's visiting their terminally ill great grandma at Otamarama rest home a few weeks ago. They both had to wear full PPE protection gear to be safe for their Grandma. It's a gorgeous photo and made a very old 93 year old lady so happy 😊

She told them they looked like moon walkers. It was lovely to watch them together. Our granddaughters live next door. I often go scooting while they bike with me on the bike tracks in Tasman and Mapua. Their great grandma loves them to bits. I'm sure it will make you smile.

Best wishes to you all.
Beth xxx

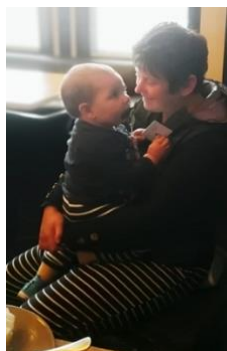


Zoe 10, Pepa 8

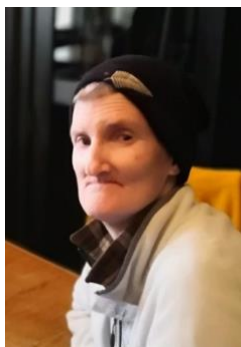


Southland Scleroderma Group

Heather bring us up-to-date with happenings from down in Southland..



Clare and her Grandson



Kimberley



The group at Buster Crabb in July.



A group of we Southlanders met for lunch on World Scleroderma Day. Jenny timed it well with it being Level 1. Clare brought her grandson, he looked delightful in he and his nana's unintentional choice of matching leggings.

We caught up with how we all coped with the Level 4 lockdown and the consensus of those attending was that we did manage OK. Nigel, who owns a photographic store, was being kept very busy processing orders that people had been sorting out during the lockdown. Kimberley is planning on moving to Ashburton, we will miss her at our meetings.

We discussed our upcoming seminar for the end of September, but alas circumstances overtook us and we were unable to carry it out. Thanks to Jenny for her preplanning and the speakers who had planned to join us from Dunedin, we look forward to next year when we will hopefully be able to hold this.

Best wishes, Heather

Christchurch Scleroderma Group

The Christchurch ladies, Barb, Chris, Janine and Carolyn met up on Saturday 26th September. Lots of talking and laughs. We learnt about how long pace maker batteries last, and about sleep apnoea. Does anyone know if there is a connection between pacemakers and Scleroderma?

We'd like to wish Glyns Hemi a very happy 80th birthday on 1st October. Have a wonderful time celebrating with your family.

Take care everyone, keep safe.

Carolyn Barkhausen sent in a photo of pure wool premature baby beanies and booties which she knits for Christchurch Women's Hospital.

Thank you Carolyn, they are beautiful and such a thoughtful thing to do.



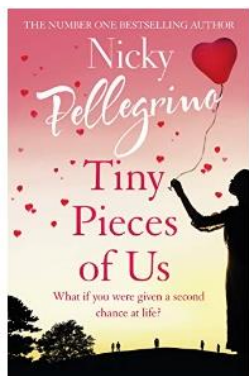
Book Club:

Welcome to a new section of the newsletter we have added.

At a recent zoom meeting, members mentioned books/videos/films they wanted to share with other members. The titles are listed below:

Readers are welcome to submit their favourite book, video or film...

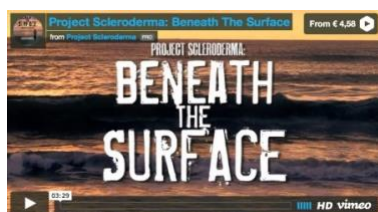
TINY PIECES OF US by Nicky Pellegrino



Vivi Palmer knows what it's like to live life carefully. Born with a heart defect, she was given a second chance after a transplant, but has never quite dared to make the most of it. Until she comes face-to-face with her donor's mother, Grace, who wants something in return for Vivi's second-hand heart: her help to find all the other people who have tiny pieces of her son.

Reluctantly drawn into Grace's mission, Vivi's journalist training takes over as one by one she tracks down a small group of strangers. As their lives intertwine Vivi finds herself with a new kind of family, and by finding out more about all the pieces that make up the many parts of her, Vivi might just discover a whole new world waiting for her...

Project Scleroderma: Beneath the Surface – video



This video has recently gained popularity, it was presented on the Oprah show and is highly anticipated by the scleroderma community.

But what is this project and how was it started? Christy McCaffrey lost her mother to scleroderma in September of 2009 and she began to think about what she could do to help fight the disease. As time went by, the idea to produce a documentary film started to mature with the help of other people involved in the scleroderma community.

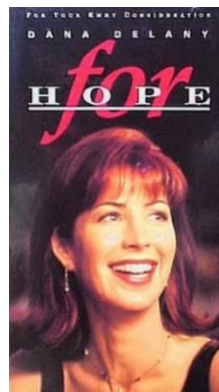
Narrated by Bob Saget, Project Scleroderma: Beneath The Surface is a film that documents the grass-roots mission of a young woman from Philadelphia working to raise awareness for a scarcely known disease that took her mother's life. In this highly inspirational and hopeful story, viewers follow Christy McCaffrey as she works diligently to create a global movement to rally behind the patients who are suffering from this terrible disease.

With the help of social media outlets, Christy connects to Scleroderma patients all over the world offering them a voice in this film as a platform to champion for their own

cause. The film is an intimate look into the everyday struggles and painful setbacks of Scleroderma patients blended with highly educational details about the disease from leading doctors and researchers to illustrate the primary message: "Scleroderma awareness simply cannot wait."

www.ProjectScleroderma.com

FOR HOPE 1996 ~ Scleroderma~ Bob Saget Sister ~ FULL MOVIE



For Hope is a 1996 American made-for-television drama film starring Dana Delany and directed by Bob Saget. Based on Saget's sister Gay, who passed away from complications of scleroderma.

The movie showed the experience of a young woman fatally afflicted with the disease scleroderma. Other cast members included Tracy Nelson and Chris Demetral.

Dana Delany had to have some significant prosthetic makeup applied to simulate the various degrees of disfigurement the main character, Hope, experienced as a result of the disease.[1]

Bob Saget's point of this movie was not for it to be some fictional drama only to entertain it's viewers. His intention was to raise awareness of a very difficult and sad disease, called Scleroderma, that most people haven't even heard of but does effect more that several million people, that claimed the life of his sister. This movie is about her battle with that disease.

HOLDING ON FOR DEAR LIFE by Liz DeVivo



In 2000, Liz DeVivo was a young mother and a Social Worker when she became ill with Scleroderma. Months later, she was devastated when diagnosed with another rare disease, severe Pulmonary Hypertension. The two rare illnesses made for a very poor prognosis and her health rapidly deteriorated, her only hope became a transplant.... What follows is an uplifting, sometimes funny, heart-breaking, gritty and raw tale of how she made it through not only her illnesses, but her transplant and all the bumps, small pebbles and huge boulders, along the way.

Liz DeVivo is on Facebook, and one of our members purchased her book and was lucky enough to get Liz to sign it for her.



Upcoming Events:

Southland

We are having our next get together lunch at **12pm on the 8th November 2020 at Thomas Green in Gore**. It's been so long since we caught up it will be fantastic to see everyone again.

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

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

Waipa

Looking for fellow Scleroderma folk who live in Cambridge, Te Awamutu or even Morrinsville to come and join Susil and I once or twice a month. Just the two of us. We meet lunch times but are open to meet Saturday afternoons. Depends on what suits really. We chat, share resources, ideas, networks anything really. Open to zoom as well. Let's endeavour to support each other as best we can.

Contact:

Erena: glenanderena@xtra.co.nz
0211869680

Waikato

We meet once a month at **Robert Harris Café, Chartwell Hamilton**.

Next coffee group:

Date: Tuesday 6th October

Place: Robert Harris

Time: 10.00am

Last Meeting for the year:

Date: Saturday 28th November

Event: Xmas Luncheon

Place: St Andrews Golf Club - Matte Black Cafe

Time: 11.30pm

Note: Secret Santa gift under \$10. Will need to know who is coming later. Upstairs, lift available

Please email to linda.bell@hotmail.co.nz to confirm.

Linda Bell: 07 8535434
027 548 1214

Christchurch

Our hard core group of ladies still meet every couple of months in Christchurch at the **Merivale McDonalds Community Rooms**. A good time is had by all, they have recently had a couple of new people join with them, but they welcome more to come along too.

Please contact Carolyn Barkhausen if you would like to join in, you would be most welcome.

Email: barkman@xnet.co.nz

Wellington

Christmas Shared Lunch

Date: 21st November

Place: Hardwick Smith Lounge Norfolk Street, Belmont, Lower Hutt

Time: 1.30pm - 4pm

There will be a Christmas Raffle or two, look forward to seeing everyone again.

Please contact Dianne Purdie

diannepurdie@xtra.co.nz or Phone 04 479 5548 if you would like to come.

Thought for the day:

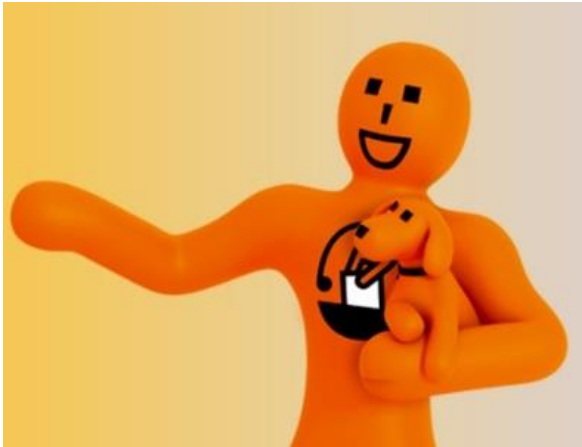
"To plant a garden is to believe in tomorrow"



Events & Happenings:

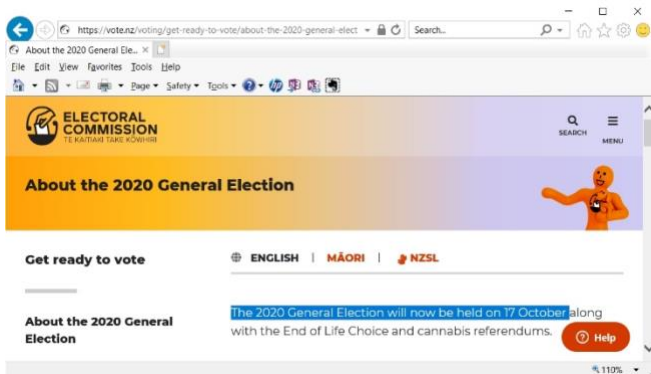
Don't forget to Vote in the
General Election on

17th of October 2020



The 2020 General Election will now be held on 17 October along with the End of Life Choice and cannabis referendums.

Visit the voting website (URL address on image below) to get all the information.



NOTICE BOARD



Auckland moved
to Covid-19
Level 2 from
Midnight 23/09/20

Rest of NZ
Covid-19
Level 1 from
midnight 21/09/20

Next Zoom
Meeting
24th October
1.30pm – 4pm

WANTED:

- News, Items
- Experience
- Achievements
- Jokes/ Recipes



Noticeboard:

Wellington support group meets:

Saturday 21st Nov 2020 1.30pm to 4.00pm

Venue:

Hardwick Smith Lounge, Belmont Domain, Lower Hutt

Christchurch support group meets:

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 8th Nov 2020

12pm

Venue:

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.

Does your area plan a meeting? For times, venue and directions to all meetings that we know about:

www.scleroderma.org.nz/calendar/

Contacts:

Find a Scleroderma a 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

Waipa:

Erena Bruce, Email:

glenanderena@xtra.co.nz

Palmerston North:

Dianne Purdie, Email:

diannepurdie@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.

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diannepurdie@xtra.co.nz

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Secretary:

Jane Sainsbury

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Gordon Purdie

gordon.purdie@xtra.co.nz

Newsletter:

Tina McLean

altinamclean@xtra.co.nz

Jenny Andrews

jennyred@xtra.co.nz



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.

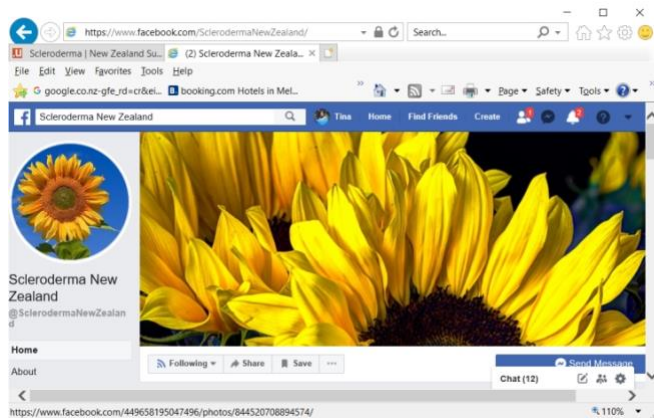
Our Website address Link is as shown below: -

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



Link to our Scleroderma NZ Facebook page.

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



Link to our Auckland Facebook page as shown below: -

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



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

Virtual Support Group Meetings

Due to the uncertainty of things with Covid-19 we are still offering Virtual Zoom Meetings for those who do not wish to attend a meeting in person, or if we are unable to hold them in person. This keeps us involved and in touch with each other. Wellington are not having their monthly coffee group so it has been replaced with the zoom meeting. The next one being Saturday 24th October at 1.30pm. (see below)

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.

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 will need to think about not meeting in our groups until the course of covid -19 is clear and hopefully a vaccine in the near future, but that could be at least one year away.

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



Due to Covid-19 Virus, we are still offering Zoom meetings....

NEXT ZOOM MEETING:

Topic: Scleroderma NZ Zoom meeting

Time: Saturday Oct 24th, 2020 1:30pm - 4pm Nationwide.

Dianne will send out the link to join in. If you do not receive this by the 17th, please contact Dianne or Tina.

