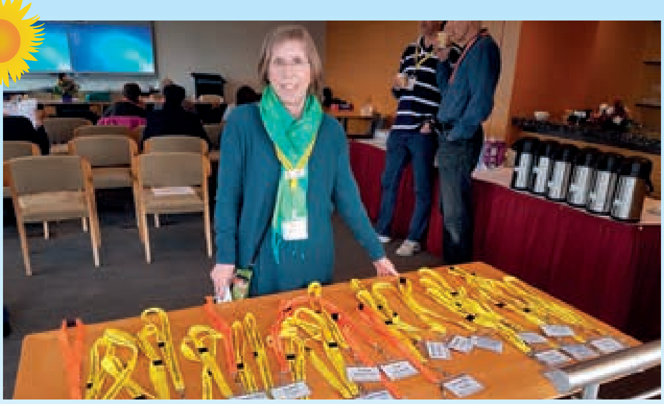
SUMMER
scleroderma victoria
NEWSLETTER SUMMER 2018
EDITION
149

Scleroderma Victoria 38th Annual General Meeting



Committee Member Jane Ryder taking registrations on the day.

Scleroderma Victoria Committee: Louise Inglese, Iain Pizzey, Jennene Caton, Amanda Lawrie-Jones, Belinda McMaster, Judy Browning, Bruce Mannion, Jane Ryder.

Amanda Lawrie-Jones presenting Iain Pizzey with the Commonwealth Bank Treasurer's Award.

Bruce Mannion accepting the Certificate of Appreciation for Margaret Angus.

Scleroderma Victoria held their 38th AGM on November 24th with around 40 members attending. One of the highlights was to acknowledge the great work that the Committee have done in the past year with an array of different initiatives. It was incredible to see that we have increased our annual income by 102%.

On the day, we had a raffle and merchandise sales which raised $330. Dr Wendy Stevens from St Vincent's Hospital came along to present on the current research progress from around the world. Our Treasurer Iain Pizzey was acknowledged with the Commonwealth Bank Australia Treasurer's award for outstanding efforts for not for profits. Several members were presented with Certificates of Appreciation for their contributions as volunteers to Scleroderma Victoria. Thank you to Margaret Angus, Noreen Wheeler and Shirley Hess.

We would also like to welcome a new committee member Margaret Hayes, who is part of the Mornington Support Group and a member of Scleroderma Victoria. We look forward to having Margaret on board for 2019 to help us progress Scleroderma Victoria's strategy.

Thank you to all of our members who came along despite Melbourne's unpredictable weather.

PRESIDENTS REPORT

We are at the tail end of the year and before you know it 2019 will be knocking on our door! There will be lots to celebrate for Scleroderma Victoria on what we have accomplished so far in 2018, and we already know that next year will be even bigger and better.

As for the last couple of months, we are continuing to build on our Support Groups, and further enhance community involvement. Our Mornington group got together for a bus trip to our More Than Skin Deep Fashion Parade, and more of our Support Groups have had Nutritionist Samantha Gemmell speak to educate our members on wellness and nutrition. Please remember you are not alone, and we welcome new Scleroderma Victoria members at Support Groups at any time. If you are interested in joining or starting a Support Group in your area, please email supportgroups@sclerodermavictoria.com.au.

It was back by popular demand, and it entirely lived up to its expectations. The More Than Skin Deep Fashion Parade at Collingwood Town Hall provided some fun and great food enjoyed by all. The raffle and auction were once again a huge hit, and just about every table went home with something. Liz Davenport shone with her 'retro' clothing line and we would like to offer a special thank you to Liz for being a great supporter to our cause. We would also like to thank the Mayor of City of Yarra Daniel Nguyen for coming along and supporting Scleroderma Victoria as a not for profit in their municipality. The star of the show was our own St Vincent's Hospital Dr Mandy Nikpour, showing off her 'fashionista' style on the catwalk. Our volunteers on the day were incredible, and we could not have done it without them – thank you to you all.

The President, Amanda Lawrie-Jones and Mayor of City of Yarra, Daniel Nguyen

We had the opportunity to showcase our new Scleroderma Victoria short video at the Fashion Parade, and if you missed it, you can view this on our Facebook and Twitter pages, or on our own YouTube site. Please share and help us spread the word on Scleroderma.

Thank you to my wonderful Committee who are always devoted to ensuring we continue to support our Scleroderma Victoria members and supporters.

Amanda Lawrie-Jones
President, Scleroderma Victoria

40th Anniversary

Scleroderma Victoria Incorporated began in 1979 to support people who live with Systemic Sclerosis.

We are surprised ourselves, but 2019 will be Scleroderma Victoria's 40th anniversary. We were formed in 1979 and have certainly come a long way with many accomplishments over many years. Our Committee will endeavor to find many ways to commemorate this occasion, acknowledging past and present individuals that have kept our Scleroderma community in Victoria strong and supportive.

If you or someone you know would like to share a memorable event or person who had an impact on Scleroderma Victoria or our community over the past 40 years, please email us at newsletter@sclerodermavictoria.com.au

Stay tuned for more on how we will mark the occasion in 2019!

Scleroderma Victoria's Strategic Plan 2018-2020

As a commitment to our scleroderma community, we have developed a strategic plan to outline our direction over the next few years. We will ensure you know how we will deliver improved outcomes for Scleroderma Victoria and the communities we serve.

The key focus of Scleroderma Victoria for 2018/19 is to expand and professionalise our Support Groups with additional longer-term goals to broaden our awareness campaigns and evolve as a stronger organisation with clear and transparent governance.

You can access our Strategy 2018 – 2020 on our website under 'How we do it'.

SCLERODERMA VICTORIA

STRATEGY

Sclermaderma Victoria Incorporated

2018 - 2020

Fashion Parade a huge success

$9400 raised for Research

Scleroderma Victoria's More Than Skin Deep Fashion Parade raised $9400 to be put towards Scleroderma Research.

The event in the Collingwood Town Hall was a huge success. If you missed it you had better make sure you don't miss it next year!

It was bigger and better than last year's, and we can't wait to do it again.

The event was kicked off by our President Amanda Lawrie-Jones, and our Master of Ceremony for the day was the well-known TV presenter Marianne Van Dorslar. We had some special guests attend, including the Mayor of Yarra City Council Daniel Nguyen.

Liz Davenport showcased her spectacular history as a renowned Australian designer with her 40 years of fashion. Liz chronicled her ensemble of stunning designs, including 'Save the Forest' (when Liz got arrested!), 'Blue Wren', 'Queen Sirikit of Thailand Silk and her signature collection.

We are very grateful for Liz and her team in helping us raise awareness of scleroderma. In appreciation she was presented with the Sunflower Hero Ambassador award by our President, Amanda Lawrie-Jones.

There was a very a familiar face to many too – both on the runway and in our Question and Answer session – none other than our own Dr Mandy Nikpour.

It was a delight for her to share her experience as a health professional and of patients with scleroderma, as well as her 'fashionista' style strutting her stuff on the catwalk!

All our models were incredible, and we would like to say a huge thank you to them for volunteering their time.

Our hard-working models were –

Fur Wale
Lucia Hou
Amanda Louey-Tran
Celina Lazarus
Azrum Caglayancay
Lina Thai

...and our own Dr Mandy Nikpour Lazarus

The fun didn't stop there! Our High Tea and Tim Adams sparkling wine were as delicious as last year. It was accompanied by the talented Mao and Bec and their charming music.

To liven the pace of the day, Paul Richards from Bekdon Richards Real Estate ramped things up with his Live Auction where bids and banter filled the room and all items were sold.

Our exciting Lucky Bag Raffle proved to be a winner yet again, where you get to choose the prize you want to win – and there were plenty of winners from donations by our generous sponsors as listed below.


The audience enjoying Scleroderma Victoria's new video at the Fashion Parade.

Major Sponsors:

- Liz Davenport
- City of Yarra
- GB Galvanizing
- Wilson Group

Support Sponsors:

- Mao & Bec
- Promo Movie Productions
- Bekdon Richards Real Estate
- Sarah McMaster Make-Up
- Tim Adams Wines
- Fabulous Catering
- Secret Blossom

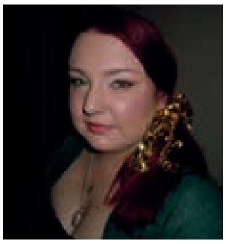
Auction Sponsors:

- Wilson One
- Tilnak Photography Fine Art and Education
- Dulux
- Next G Electrical
- Bunnings Warehouse
- Essendon FC

Raffle Sponsors:

- The Grand Richmond
- Cockatoo Grove
- Essendon FC
- Jimmy Fox
- The Nut Bloke
- GT Detailing
- Strintzos Group
- Tilnak Photography Fine Art and Education
- Kiva Designs
- Beechworth Honey
- Alex Tullio Consulting
- Nepean Complete Cleaning Services

Meet our Vice-President



Belinda McMaster

Belinda came along to our AGM in November 2014 to help her Mum (Jennene Caton our Secretary) set up the laptop and audio-visual equipment. She proved to be so capable on the day that, with a bit of encouragement from Mum, ended up being elected onto our committee.

She subsequently accepted the position of Vice-President at our AGM in November 2015.

In this role she supports our President, (Amanda Lawrie-Jones) and represents Scleroderma Victoria at every opportunity.

Belinda is employed as a Lawyer with the Victorian Government and her legal skills have proven to be an asset to our organisation.

Since joining our committee, Belinda has done a lot of work behind the scenes. She has been the event organiser for our Conferences in 2015 and 2017 and our AGM in 2016 and 2018. She has worked on several policy and planning documents including our Strategic Plan 2018 – 2020 and she ensures ongoing compliance with our Model Rules.

As the youngest member of our committee, and one of only two members who do not have Scleroderma, she brings a fresh and energetic perspective to our organisation.

Why did you become Vice-President?

I had been a committee member for 12 months when the Vice-Presidents position became vacant.

My Mum has had Scleroderma for 12 years, so I am well aware of the condition, and how it affects people's lives.

As I don't have the condition, but I have a very good understanding of it, I thought I could bring a different perspective to the role. I also have legal, planning and organising skills that I thought could be an asset in this position.

I also wanted to continue helping Mum and the other committee members who I had become friends with. By this time, I had also met a lot of our members, and I wanted to represent them in the best way that I could.

How long have you been Vice-President?

Since November 2015

What is the best thing about being Vice-President?

I have really enjoyed our events, such as the "More Than Skin Deep" Fashion Parade, and the annual World Scleroderma Day luncheons.

I have enjoyed meeting our Ambassador; Dyson Heppell and seeing how he has lifted the profile of Scleroderma Victoria.

I have also enjoyed meeting so many of the wonderful Doctors who specialise in Scleroderma and conduct research in the hope of finding a cure for this disease. Of course, I also enjoy doing my bit to help our members, who live with this disease every day.

What are your outside interests?

I enjoy traveling to new and exciting places and crochet is my creative hobby.

A MEMBER'S PERSPECTIVE

'I was not alone on this journey'

by Sylvia Ferris
NE Support Group

In May/June 2017 I began to get little things going wrong with me and despite many visits to the GP it returned no results.I had just turned 70 and was going to the gym three times a week, looking after husband, son, daughter and grandchildren.

I had taken short holiday breaks and planned a much larger holiday for 2018. Life was good and busy.

My beautiful hands began to swell, and my fingertips were discoloured and very sore or, so I thought.

After more visits to the GP I still had no further information.

After a lot of time I was sent to a rheumatologist with the diagnosis of Lupus. I was told by the rheumatologist I had scleroderma.

I could not say the word let alone spell it. It is a chronic but not fatal disease, I was told. No more information was given.

A friend said she had a friend who was part of a Scleroderma Support Group and would I like to meet her? "Yes please" was my reply.

Jane came to my home, filled in the gaps and my/our disease became a lot easier to understand.

I was not alone on this journey and I had friends that understood what I was talking about. I have joined the NE Support Group and without the help of the group life would have been a little harder.

I would like to say all the rheumatologists, heart specialist, lung specialist and thoracic surgeon and nursing staff have also been wonderful.

In the next few months I'll be travelling again and enjoying life again. Life is better than I first expected it would be. The scleroderma support group helps and supports each other.

Thank you.

Sunflowers bloom at wedding

Bridget Naughton was keen to raise awareness of Scleroderma, even on her wedding day.

Bridget and Matthew Hollway were married on Saturday October 20, 2018, and scleroderma was never too far away during the joyous occasion.

To achieve this Bridget contacted our Secretary, Jennene, early in the year and collected sunflower pin badges, wristbands, brochures and sunflower seeds to make into a bonbonniere for her 80 guests.

She also made a very generous donation to Scleroderma Victoria on behalf of her guests. This donation was then matched by her employer; AbbVie Pty Ltd.

The bonbonniere reads; "10 years ago Bridget was diagnosed with Scleroderma, an extremely rare auto-immune disease. A donation to Scleroderma Victoria has been made on your behalf to ensure research continues into the management and future cure of this disease. Please sow the seeds and watch them bloom, just like the love of the Bride and Groom".

Our President, Amanda Lawrie-Jones, sent a "telegram" on behalf of our members which was read out by the MC during the reception.

It concluded with the quote "Keep your face to the sunshine and you cannot see the shadow. It's what sunflowers do".

Thank you, Bridget and Matthew, for including Scleroderma Victoria in your special day.

May you have a long and happy life together.

Sunflower Hero

Our More Thank Skin Deep 2018 Fashion Parade would not have been possible without the generosity of Liz Davenport and her team. Our President Amanda Lawrie-Jones presented Liz with a special Sunflower Hero award for her contributions to Scleroderma Victoria.

Liz was thrilled to receive the award and provided some great feedback on how we put the parade together. Our own volunteers who assisted the models, Julie and Joanne, were amazing and generally it would take 5 to 6 assistants to ensure a show runs smoothly. In addition, our own volunteer models are some of the most professional she has worked with.

This was the first time that Liz Davenport had her life's work shown on the catwalk in the one show, it was a proud moment to have 40 years of her work put together for a great cause.

Liz is looking forward to being involved further with Scleroderma Victoria to fulfil her role as a Sunflower Hero at future events.

Become a Sunflower Hero today – please see our website for more information or you can contact sunflowerheroes@sclerodermavictoria.com.au

The gift of mobility

by Jane,
Committee Member

Scleroderma Victoria would like to thank Janice Burke and family for the generous gift of a mobility scooter. Earlier this year Janice offered us the scooter used by her late husband Dennis, a fellow scleroderma sufferer. It was collected from their home in Whittlesea and if you could benefit from the use of this scooter, please contact our office on 03 92883651 (please leave a message) or email enq@sclerodermavictoria.com.au.

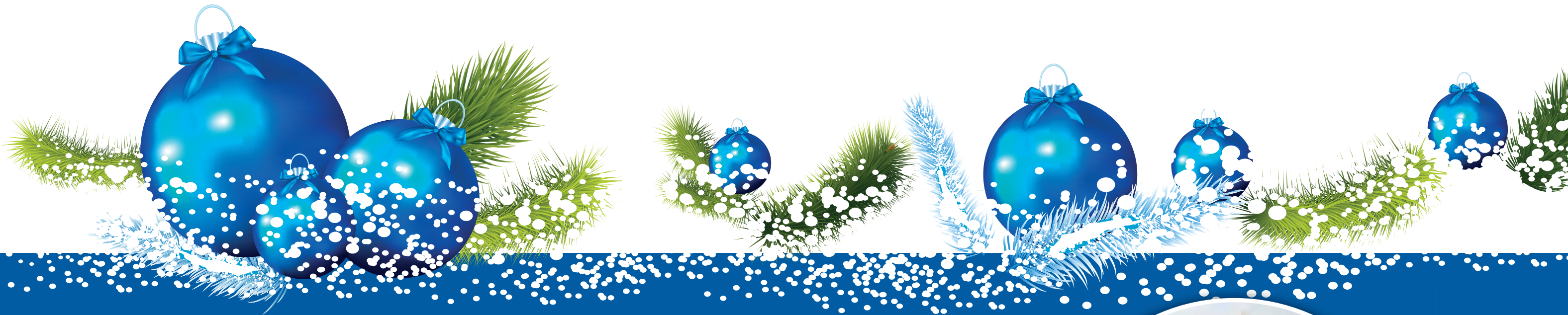
Mornington Support Group Wellness and Nutrition Workshop

Samantha Gemmell once again presented at our Mornington Support Group on Wellness and Nutrition at Bentons Square Community Centre on November 17. There was a mixture of Scleroderma Victoria members and their families in attendance providing all with enthusiastic discussions and informative ideas on gut health, food combinations and practical ways to support our bodies with food and supplements. It was an excellent day and a wonderful way to finish off our year.

Bendigo Support Group

As the year comes to a close, the Bendigo Support Group hosted by Judy Browning came together on November 28 to celebrate another year of gently supporting and caring for each other. 2019 promises to be bigger than ever and our Bendigo members are looking forward to coming back together on January 16 and all new members are welcome.

For more information, contact Judy Browning via email socialmedia@sclerodermavictoria.com.au



Give a gift this festive season

As our year comes to a close and we think about the season of gift-giving with our family and friends, why not grant your loved ones a Scleroderma Victoria membership. It is a great way to support you in your journey with scleroderma by raising awareness of the condition, as well as helping us to 'spread the word'. We welcome as many members as possible and look forward to meeting you all in person at our amazing events for 2019!

Scleroderma Victoria's More T

han Skin Deep Fashion Parade

Sunflowers for scleroderma

By Zoe Senior
Coordinator of Sunflowers for Scleroderma Fundraiser - Tasmania

My daughter Alysha was diagnosed with scleroderma 12 months ago at the age of 20.

As a parent, when something is wrong with your child, you are wanting to fix it and since scleroderma is something I had no control over I felt helpless and I needed to feel like I was doing something to help.

Our family and friends had never heard of scleroderma before Alysha's diagnosis and nobody really knew what it was. This is when i self-appointed myself to become an advocate to find out more about this disease and educate the people close to us and create awareness in our home town ... this had become my mission!

Being a member of the Scleroderma Australia Facebook page, I would see posts about different fundraising events around the country, but none of those in Tasmania, this is when the "Sunflowers for Scleroderma" campaign was born.

With advice and encouragement from Scleroderma Australia I was determined to make as many people in my home town aware of what scleroderma is and raise as much money as I could to help.

On August 11, 2018 at our local football club rooms in New Norfolk, Tasmania, we held a fundraising event which we named "sunflowers for scleroderma". Close to 170 people attended this event and we had an enormous amount of feedback on how much everyone enjoyed the night.

We started out with games of bingo, then went on to a quick few rounds of trivia! There were raffles, lucky door prizes, lucky sunflowers and pop the balloon games as well as a best dressed parade!

While guests enjoyed supper, we gave a short talk about scleroderma which included what it is and how it affects suffers.

We finished off with a karaoke competition then followed with a DJ for the rest of the evening!

Our night was a huge success and there are a lot of people in our community who now know what scleroderma is, which was my main aim.

The total raised on the night was $5732.40.

Scleroderma Australia as a whole do a wonderful job with raising funds for research and in time hopefully there will one day be a cure not only for my daughter, but for all sufferers.

Our "Sunflowers for Scleroderma" event was a fantastic night that is still being talked about which makes me think about turning this into an annual event!

Tasmania update

Sally Westbury has played a vital role in keeping Victoria and Tasmania connected in the scleroderma community. Due to a recent move Sally has stepped down as the support group coordinator and as a Committee member of Scleroderma Victoria. Her support and commitment in coordinating contacts and the support group has been invaluable to ensure people with scleroderma were not alone. We would like to thank Sally for her support as a key connection in Tasmania.

The Tasmanian support group in Hobart is still meeting, and if you would like to know more or take on being a support group leader, please email us at supportgroups@sclerodermavictoria.com.au

New members always welcome

by Pauline Sim,
LSS Co-ordinator

The LSS Friendship Group in South Australia is a very friendly & supportive support group and we always welcome new members. (We are part of Arthritis SA so please contact them for full details about officially joining).

We meet informally on the 1st Friday of the month at Rumours Cafe (Wohlers Homeware & Gifts on Richmond Road). There is also a western suburbs support group that meets on the 3rd Wednesday of the month at Red Cloud Cafe (Grange Road, Fulham Gardens)

On September 13th, Arthritis SA organised a seminar entitled 'A Positive Mind. A Beautiful Body'. Expert speakers included Psychologist Dr Emma Johnston and Dermatologist Dr Rachel Manifold.

Issues such as positive body image at any age and size and positive and practical ways to live well with different health issues. Members who attended spoke very highly of the event and the speakers.

On a personal note, I spent this past winter in Singapore and I loved every minute of it! My twin sister, Julie, who also has Scleroderma, joined me for two weeks and while in Singapore we had the opportunity to meet up with Sclerowarriors's Haslina, for coffee & a chat. Haslina has worsening PAH so our catch-up was fairly brief, but lovely all the same.

From the 7th to the 19th September five friends and I embarked on a pilgrimage walk from Le Puy en Velay to Conques, which is considered to be the most scenic but most difficult section of France's Compostella pilgrimage trail.

The Le Puy Camino (Chemin St Jacques, Via Podiensis or Way of St James) was an experience of a lifetime!

When I agreed to walk last April, I started training, had exercise physiology sessions, full yearly set of tests plus a heart echo stress test and I was fully prepared for every contingency!

It was just as well!

From the start with the welcoming Pilgrim Mass (where a sunflower was positioned at the feet of St James…a good omen for sure!) in the Cathedral in Le Puy to the end, 210 kilometres, 12 days later in Conques, the journey through many beautiful small towns was simply incredible but very challenging!

The terrain was varied from lovely country lanes to rough, rocky paths with many steep descents & ascents. I ended many days beyond exhausted!

I met some wonderful people from all over the world and I gave away many kangaroo badges!

I will never forget the kindness & thoughtfulness of my friends who were always mindful of my Scleroderma condition. I feel thankful, grateful and blessed to have completed my Way of St James experience!

Lunch for members of the LSS Friendship Group in Adelaide.

Julie, Haslina and Pauline in Singapore.

Pauline on her pilgrimage.

Dental hygiene important in Scleroderma

by Jessica Massengale, Scleroderma News

The very first step in the digestion process begins in the mouth. For someone with scleroderma, simply chewing food can be exhausting.

Different disease factors affect one's dental hygiene, but various steps can be taken to try to maintain a good environment within the oral cavity. Over 20 per cent of scleroderma patients have Sjogren's syndrome. The disease is characterised by malfunctioning saliva and mucous glands, so essentially it leaves one with dry eyes and mouth, among other issues. A human can produce enough saliva in a lifetime to fill two swimming pools. There are special enzymes in our saliva that help to break down the composition of food, and without them, things can get complicated. Biotene is a common mouth rinse used by many patients to combat dry mouth. Xylamelt tablets also are used.

The tightening caused by scleroderma can shrink the opening of one's mouth to a point in which even biting a sandwich becomes difficult. The reality is hard to face, as sandwiches get cut into fours and eaten with a fork. There's something satisfying about taking a big bite of a delicious sandwich or burger, and that is lacking with scleroderma.

Since there's less room in the mouth, little pieces of food become stuck inside the cheeks. These food particles will turn into plaque if they stay lodged in the teeth too long, so rinsing after every meal is a must. Smaller bites of food must be taken, which results in lengthy eating times. Anytime I'm eating with a group of people, I am always the last one left, finishing 30 minutes after everyone else is done.

It can make one feel self-conscious, but those around should understand with an open heart and wait patiently.

A small mouth also makes dentist visits dreadful, but regularly scheduled teeth cleanings can prevent and maintain a healthy mouth. Fear of the dentist must be overcome to proceed with this maintenance. An appointment can be scheduled with a paediatric dentist because they have smaller tools to reach the back of the mouth.

Vaseline placed around the corners of one's mouth can help ease the opening and prevent minor cuts or tears. It's important to always ask for a gentle cleaning, since receding gum lines are also very common. This is due to the face being so tight, as it begins to pull the gums downward. This recession is very hard to reverse and can sometimes be treated with a gum graft. Some patients can, unfortunately, lose teeth from the combination of all the above complications.

Following are a few items that can help keep those pearly whites in shape:

- Electric toothbrush: a child- or adult-sized toothbrush can help significantly reduce plaque.
- Water pick: helps to gently clean food that gets stuck in between teeth.
- Floss picks: scrapes and picks between teeth.
- Mouthwash: helps prevent plaque build-up.
- Fluoride toothpaste (prescription from a dentist): helps keep teeth strong.

When good dental practices are added to our daily routines, it can lessen the discomfort between dentist visits.

Our teeth are the livelihood of our bodies and must be maintained, similar to a car. Investing in these products creates one less worry on this chronic journey.

Scleroderma Victoria
Polo Shirt Order Form

I would like to order _____ polo shirts at $30.00 each (includes postage)

Ladies Sizes; 8 ____ 10 ____ 12 ____ 14 ____ 16 ____ 18 ____

Mens Sizes; S ___ M ___ L ___ XL ___ 2XL ___ 3XL ___ 4XL ___ 5XL ___

Total Amount Payable: $_______________

****Please check size charts on next page****

Name: ___________________________________ Phone: ____________________

Address: ____

________________________State: __________________Postcode: ____________

Email address: ____

Payment methods:

☐ **EFT (preferred)** ☐ Cheque ☐ Credit Card

PAYMENT BY EFT (please put "Polo" and your Surname in the reference section)

Account Name: Scleroderma Victoria Inc. Account No: 10157937 BSB: 063215

Please debit: ☐ Mastercard ☐ Visa

___ ___ ___ ___ / ___ ___ ___ ___ / ___ ___ ___ ___ / ___ ___ ___ ___ Expiry date: _____ / _____
Credit Card No.

Cardholder's Name ________________________ Signature ___________________ CCV* ___ ___ ___
*CCV Must be provided for your payment to be processed

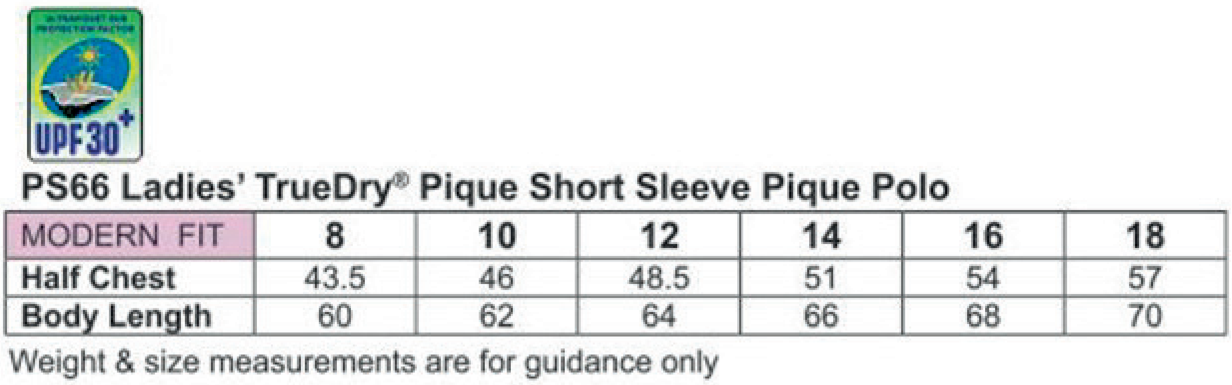
Email orders to; enq@sclerodermavictoria.com.au
or post to;

The Secretary, Scleroderma Victoria, St Vincent's Hospital,
41 Victoria Pde, Fitzroy Vic 3065

Polo Shirt Size Charts

Please measure and order sizes carefully. Scleroderma Victoria will offer exchanges, however, the return postage will be paid by the purchaser.

Ladies shirts are a very fitted style, if you prefer a more relaxed fit, please order a larger size. Ladies size 8 and 10 are also suitable children's sizes.

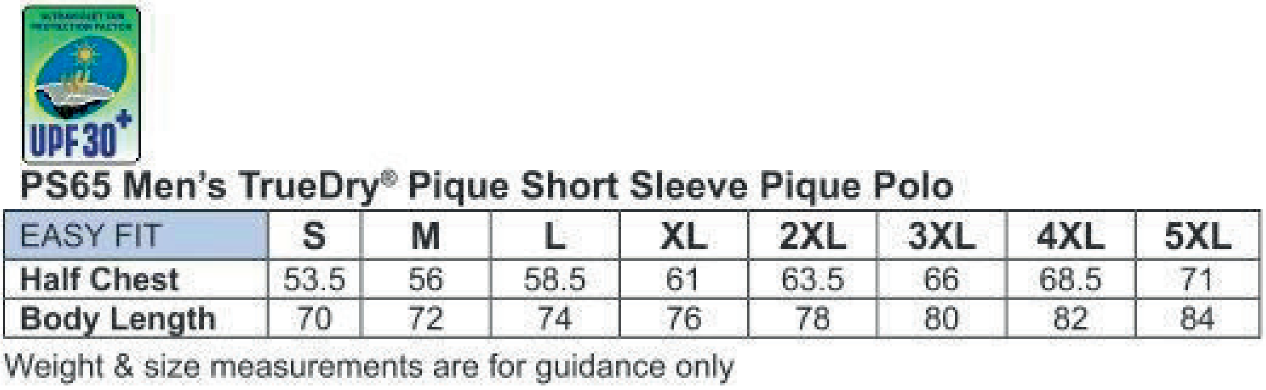


UPF30+

PS66 Ladies' TrueDry® Pique Short Sleeve Pique Polo

MODERN FIT	8	10	12	14	16	18
Half Chest	43.5	46	48.5	51	54	57
Body Length	60	62	64	66	68	70

Weight & size measurements are for guidance only



UPF30+

PS65 Men's TrueDry® Pique Short Sleeve Pique Polo

EASY FIT	S	M	L	XL	2XL	3XL	4XL	5XL
Half Chest	53.5	56	58.5	61	63.5	66	68.5	71
Body Length	70	72	74	76	78	80	82	84

Weight & size measurements are for guidance only

FROSTIES UNITE

Don’t Turn a Cold Shoulder to Painful Fingers

For Raynaud’s Awareness Month this October, Raynaud’s Association in the UK is launching a new campaign titled “Don’t Turn a Cold Shoulder to Painful Fingers.”

They’re urging sufferers, plus their doctors, friends, family and co-workers not to dismiss the pain Raynaud’s sufferers endure.

How many Frosties have been told by their physicians “move to Queensland” or “just stay warm,” without further examination.

One lady’s personal experience in the UK was with a doctor who told her “You have poor circulation, wear support hose.” She had to put her foot down and threaten not to leave her office until she could tell her what was wrong or refer her to someone who could.

Many patients in Australia have had similar experiences.

Often family, friends and co-workers may be unsympathetic to the pain of a Raynaud’s attack. Family members might think sufferers are just trying to get attention. Co-workers often grovel when asked to adjust the thermostat. Friends comment that wearing gloves in 60-degree weather looks silly.

Stand Up for the Right to Be Taken Seriously

Raynaud’s is a widespread disorder. It affects five to 10 per cent of the population, 20 per cent of all women of childbearing age (nine out of ten sufferers are female), but only 90 per cent seek treatment. And often when they do, or attempt to make their environment more comfortable, they get pushed back.

In celebration of Raynaud’s Awareness Month in the UK, the Raynaud’s Association is urging sufferers to stand up for their right to be taken seriously. They want to help fellow Frosties understand they are not alone, that they are not imagining or exaggerating their pain, and they don’t have to accept the cold shoulder treatment.

Share Your Cold Shoulder Stories

Scleroderma Victoria unashamedly supports this project. As we are just coming out of winter, we would like to hear from you with your stories of being dismissed by people you know or care about and their lack of understanding or belief that your pain and discomfort has a medical explanation.

Send your experiences to the Editor (newsletter@sclerodermavictoria.com.au), or share them on our Facebook page. We will publish them next year before the “Raynaud’s season.” Let us know if you don’t want your name published.

Together we can stop the “Cold Shoulder” treatment!

Donations to Scleroderma Victoria are tax deductable for income tax purposes

Please complete the form and return to Scleroderma Victoria, St. Vincent’s Hospital, 41 Victoria Pde, Fitzroy 3065

Name: ________________________________

Address: ______________________________

____

Phone: ________________________________

Email: ________________________________

☐ I would like further information on how I can support Scleroderma Victoria

Credit Card: ☐ Visa ☐ Mastercard

Card No: __ __ __ __ / __ __ __ __ / __ __ __ __ / __ __ __ __

CCV: __ __ __ **Amount:** ____________________

Expiry Date: __ __ /__ __ **Signature:** ________________

Cardholder’s name: ______________________________

Direct Credit: ☐ BSB: 063-215 Acct No: 1015 7937
Reference: Your name

Cure in sight for Calcinosis

Two professors from Manchester University in the UK believe that in a few short years there could be a clinically proven topical treatment for calcinosis.

Professor Ariane Herrick, based in Manchester, is collaborating with Professor Richard Winpenny, also at the University of Manchester, to investigate the possibility of a treatment that could dissolve the bony lumps under the skin.

Having worked together previously, their work has demonstrated that the lumps are primarily formed of a substance called carbonate hydroxyapatite.

They are combining their areas of expertise, chemistry and medicine, to create a treatment that can be applied to the skin and then pass through the skin barrier to dissolve the bony lumps formed because of calcinosis.

They're investigating the properties of various topical substances in order to determine which one will be most efficacious in dissolving the deposits without any harm to the surrounding healthy tissue.

They are also collaborating to better characterise the lumps so that they can determine what else the deposits are made of.

Funding from Scleroderma Raynaud's UK has meant that four substances that were identified as part of this study are now being studied further to determine if they are suitable for use as topical agents in humans.

This means that in a few short years, there could be a clinically proven topical treatment for calcinosis that is readily available for this painful condition.

What is Calcinosis?

Calcinosis is the formation of painful white calcium lumps that form under the skin on hands, feet and other body areas.

They can form in small lumps and clusters and in some cases, they break through the skin. Calcinosis occurs in 40 per cent of scleroderma patients and the cause is still unknown.

At the moment there is no cure for calcinosis.

There is also no real treatment, with patients being told to seek regular medical advice in case of an infection due to skin breakage. Surgery is sometimes used to remove larger calcium masses, however, that is considered a crude approach and does not completely remove the lumps.

Scleroderma Victoria Donations

AbbVie Pty Ltd
Bendigo Bank
Estate of Beryl Jean Hogben
Ithacan Philanthropic Society
Lions Club of Maryborough
Pacific Hydro
UFS Medical Ballarat
Eileen Beaton
Margery Cairns
Val Corbett
Joy Guinane
Ewa Haire
Nicoletta Kandyliotis
Peter Kandyliotis
Kirsty Lovejoy
Kelly Lyngcoln
Peter McGinnes
Bridget Naughton
Gilda Schachter
Kerry Schrammeijer
Barb Shannahan
Margaret Wallis
James Waring
Mathew Barnes
Strintzos Properties
Annette Gaiardo
Christine and John Dignam

SCLERODERMA VICTORIA DIRECTORY

Incorporation No. A001798A
ABN 45 674 166 348
All correspondence to: Scleroderma Victoria,
St. Vincent's Hospital, 41 Victoria Parade, Fitzroy,
Victoria 3065 or phone 9288 3651
Website: www.sclerodermavictoria.com.au
Email: enq@sclerodermavictoria.com.au

Our office is attended Tuesday mornings from 10am to 12 Noon. Phone messages may be left on our message service.

MANAGEMENT COMMITTEE

President:
Amanda Lawrie-Jones
E: president@sclerodermavictoria.com.au
Vice President:
Belinda McMaster
E: vicepresident@sclerodermavictoria.com.au
Secretary and Operations Manager:
Jennene Caton
E: secretary@sclerodermavictoria.com.au
Treasurer:
Iain Pizzey
E: treasurer@sclerodermavictoria.com.au

COMMITTEE MEMBERS

Judy Browning
Bruce Manion
Gene Swinstead
Jane Rhyder
Margaret Hayes
Louise Inglese

NEWSLETTER EDITOR

Gene Swinstead
E: newsletter@sclerodermavictoria.com.au

VICTORIAN SUPPORT GROUPS

Co-ordinator - Judy Browning (Bendigo)
(03 5437 3305)
E: socialmedia@sclerodermavictoria.com.au

Bendigo As Above.

Albury/Wodonga Kaye Dando
E: kcamry54@hotmail.com (0459 234 690)

Ballarat Paul Hadfield
E: paul.hadfield67@bigpond.com (0484 342 925)

Geelong Janelle Blight
E: dermageelong@gmail.com (0413 046 110)

Gippsland Corrie Hemming
E: corriehemming@bigpond.com (0400 331 829)

Inner South Eastern Suburbs Lynette Slade
E: l.slade@bigpond.com (9576 4066)

Mornington/Westernport Louise Inglese
E: events@sclerodermavictoria.com.au

Narre Warren Barbara Handasyde (0457 123 447)
North Eastern Suburbs Jane Rhyder
E: janerhyder@optusnet.com.au (9444 6900)

Seymour Heather Hollaway
E: hthr_hollaway@yahoo.com.au (57842322)

Western Suburbs Yvonne Hoffmann
E: hhoffmann@netspace.net.au (9743 1009).

Contacts but no support group –
Cheryl Rosini - Maryborough: 03 5461 1356

Sharon Egberts - Mildura 5024 2337
E: shajoy54@gmail.com

Launceston - Margaret Murray 6391 8561