WINTER

scleroderma victoria

NEWSLETTER WINTER 2018

EDITION 148

Dyson and Harrison after the "big shave".

$CLERODERMA

WOW!

What a World Scleroderma month we had, raising the record amount of $74,311 for scleroderma research.

Highlight of the month was our Scleroderma Ambassador Dyson Heppell's "Get Behind the Beard" campaign which raised a massive $62,500. Dyson is Captain of the Essendon Football Club in the AFL.

The campaign culminated in Dyson shaving off his beard on World Scleroderma Day in front of the entire Warranwood school where his little mate Harrison Pennicott is a student.

Harrison, a Bomber fan, has a rare form of scleroderma.

Other fathers at the school joined in and had their beards shaved too.

Other fund-raising events during the month included a World Scleroderma Day lunch at The Grand Hotel in Richmond which netted $7410.

Sales of Uncle Jack watches added $4151 and the "Change 4 Scleroderma" campaign raised $250.

Scleroderma Victoria President Amanda Lawrie-Jones introduces our Scleroderma Ambassador Dyson Heppell at the World Scleroderma Day lunch at The Grand Hotel in Richmond.

FROM THE PRESIDENT
Amanda Lawrie-Jones

Victoria spreads awareness

As World Scleroderma day and the month of June awareness events concluded, it became evident that this was our most successful campaign for Scleroderma awareness in Victoria.

I have an overwhelming sense of pride and gratefulness for our hard-working and pioneering Committee, and I am very appreciative of the time and effort they put in to volunteer to make things happen.

Well done to this amazing team!

On the eve of World Scleroderma Awareness Month, our Secretary Jennene and myself had the pleasure of attending the Footy Show where our Ambassador Dyson Heppell kicked off the campaign with the Uncle Jack watch launch, as well as 'Get Behind the Beard'.

Our President Amanda (left) with Harrison

The "Scleroderma" watch from Uncle Jack with the sunflower emblem on the casing.

It was great exposure on mainstream TV, and a good feeling to get the word Scleroderma out there as a conversation starter.

Over the month, we continued to spread the word on Scleroderma, and had the 'Change for Scleroderma' or C4S fund-raiser. We asked people to collect their spare change in a jar at home throughout the month of June and at the end of the month, the change was deposited to our bank account. This campaign raised $250. If you didn't get the chance to get involved in this campaign, it is never too late to start.

'Get Behind the Beard' was the real winner, with tremendous media publicity as Dyson Heppell shaved off his beard. This was a long-awaited event for many, including young Harrison Pennicott who jumped in to have first go with the clippers. Thank you to Warranwood Primary School for holding the event, and thanks to all the kids for getting into it with their own paper-plate beards. A big thank you to Dyson too!

Uncle Jack watches collaborated with Dyson Heppell to create a series of limited edition watches, which had Dyson's initials on the front, and a sunflower on the back. Both the black and silver watches sold out fast, and we were very pleased to have Uncle Jack on board to raise funds and awareness for Scleroderma in a new and innovative way.

In promoting regional awareness, it was great to have Samantha Gemmell as a guest speaker at the Bendigo Support Group meeting in June. Sam spoke on the importance of gut-health and Scleroderma and gave plenty of great hints and tips on eating well. (See Page 5).

Once again, our third annual World Scleroderma Day lunch at The Grand was another brilliant day, with lots of great feedback. Dyson Heppell came along to do a Question and Answer session, looking rather clean and fresh with the beard gone. Great work too, to Louise from our Committee in sharing valuable information on our Support Groups throughout the State. The lunch raised a total of $7410 for scleroderma research.

A special thanks goes to our Committee member Gene and The Grand Hotel. We couldn't have done it without them and as always, the hospitality and generosity of The Grand was incredible, and we appreciate their continuous support. The Grand management have pledged to support another World Scleroderma Day lunch on June 29 next year. Put it in your diary.

On behalf of the Scleroderma Victoria Committee, I would like to thank all of our members and supporters who helped us to raise awareness and funds for World Scleroderma month in 2018. It is because of you that our month was so successful.

All of our activities during June raised a total of nearly $72,000 for research.

"Get Behind The Beard"

Over $62k raised!

World Scleroderma Day 2018 will be a day Essendon Captain Dyson Heppell won't forget in a hurry. It was the day he shaved off his beard to raise funds for Scleroderma Victoria.

Held at Warranwood Primary School and helped by his little mate Harrison, the shave off was the conclusion of a major fundraising campaign throughout June leading up to World Scleroderma Day.

Harrison is the youngest known sufferer of Scleroderma in Australia currently and only one of two in the World with his condition. Dyson is the Ambassador for Scleroderma Victoria, with his family having a direct connection to the disease through his Grandmother who died from scleroderma four years ago.

Launched on The Footy Show on Channel 9 in early June, the initial target was to raise $30,000.

The final tally by the end of the campaign was $62,500. Harrison's Mum and Dad, Leesa and Jamie, were heavily involved along with his older Brother Miller. The Warranwood School Community also got on board with fundraising and some fathers also shaving off their beards for the cause.

Come the day when the beard was to be shaved off, interest in the event was huge, with Channels 7, 9 and 10 in attendance and the major print daily, The Herald-Sun, as well as local media.

All the school children gathered in the school hall for the event, with quite a number getting into the spirit of the day by making their own cardboard beards to wear.

Media exposure was gained in the afternoon and main bulletins of the TV stations that day and the Herald-Sun ran a story and photo on page 3 in the next day's edition. Channel 7 also ran a story segment at half-time of the Essendon v North Melbourne match played on the Sunday.

The campaign couldn't have gone better from both a financial and exposure viewpoint and the number of people that now have become aware of Scleroderma has increased greatly across the wider community.

The funds raised will now be used for research, with consultation in progress with the Australian Scleroderma Interest Group (ASIG) as to how best to apply the funds.

The day was a huge success thanks to Dyson, Harrison, his family and the entire Warranwood school community. Thanks too, to everyone who made a donation through the "Get Behind The Beard" campaign.

The whole school turned out to see Dyson lose his beard.

Pictured left:
Young Harrison looks on as Dyson loses his beard.

Pictured right:
Warranwood school went to a great deal of effort to make it a day to remember.

Meet your Member

Bruce Mannion

Why did you become a Committee Member?

WHEN I was diagnosed with Scleroderma I initially found it fairly confronting. Having discovered the Facebook's of both Australia and Victoria and it's support network, I thought I may be of some value in using my business and marketing skills in raising funds and bringing awareness to Scleroderma.

How long have you been a Committee Member?

My fellow Committee Members have suffered me since Sept 2015.

What is the best thing about being involved with Scleroderma Vic?

Making a difference I think. In the scheme of things we're a small organisation, but from small steps grow big steps and our steps are definitely getting bigger.

Awareness via the media has markedly increased along with the funds we are raising.

Getting Dyson Heppell as an Ambassador has also been a great boost. He, his partner and his family have been fantastic. So easy to work with. It's also great working alongside people that have the same aim and goals.

What's your aims?

Just to measurably increase the awareness of Scleroderma within the general community and the medical profession, as well as supply more funds for ASIG and the like to find that needle in the hay stack – a cure.

Outside interests?

Scleroderma has crimped my style somewhat.

I've always owned boats, so one of my great loves to relax away from work was fishing.

Unfortunately, that's gone now as I'm not physically capable, so I keep busy with Scleroderma Victoria, mentoring my daughter in Business while she is studying, travelling and keeping the café's in my area in profit.

Photo above courtesy of Robb Cohen Photography & Video

More than 650 at patient conference

More than 650 people attended the United States Scleroderma Foundation's 20th National Patient Education Conference in Philadelphia USA last month.

I had the pleasure to attend this event which had over 50 workshops and 60 well-renowned guest speakers and facilitators from around the country.

The theme for this year's conference was 'Reach for the Cure' which provided an inspirational experience to learn about Scleroderma and of course, to connect with others whether they are just at the beginning of their journey or well into it like me.

My trip was supported by an educational grant from Actelion Pharmaceuticals.

Amanda Lawrie-Jones
President, Scleroderma Victoria.

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

Nutritional needs in Scleroderma

Nutritionist Samantha Gemmell recently gave a presentation to the Bendigo Support Group. There was a good turn-out of members and friends.

For those who were unable to attend, here is an overview of her presentation.

-by Samantha Gemmell, Nutritionist

What is holistic nutrition?

Holistic nutrition is an approach to food and lifestyle that focuses on the individual. Every one of us has individual needs, so there is not such thing as one perfect diet that suits everyone.

This approach also respects that nutrition and the food we eat can impact on every system of the body.

Every single molecule in your body is made up of something that you or your parents consumed at some point.

This shows how essential a good diet is for living a good life.

There are other factors that impact significantly on nutritional needs as well.

Medication use, lifestyle choices and stress levels can all increase the need for certain nutrients.

The Four Factors Of Nutrition.

When it comes to nutrition, there are four main factors we look at:

Intake - how much of a nutrient is consumed.

Absorption - how much is absorbed into the body

Use - how much is used up by normal body processes

Excretion - how much is removed from the body

All of these factors can be involved when it comes to scleroderma. As examples:

Intake of nutrients may be limited due to allergies or intolerances.

Absorption is limited by the hardened tissues

Use of some nutrients is higher due to the inflammation caused by scleroderma.

Excretion of nutrients is affected by kidney and bowel conditions.

So it's easy to see why nutrition is such a complex topic in scleroderma!

Gut health 101

To understand a lot of the issues with nutrition - and with Scleroderma and nutrition - we have to look at the gut.

The gut is a major line of defence for the body, keeping out nasties and letting in the good stuff. If you have issues with your gut, you have a higher chance of illness and malnutrition.

The most common issues with gut health are dysbiosis - when your gut flora are out of balance - and increased gap function permeability - commonly called "leaky gut".

The gaps between cells in the gut are called "gap junctions". If the gut is healthy, the junctions are tight, and don't let bad things through. But when it's unhealthy, the junctions become loose and allow molecules through.

This puts the body on high alert and long-term can lead to autoimmune disease.

People with scleroderma are much more likely to have gut issues. Scleroderma impacts on the gut by:

Hardened tissues preventing the absorption of essential nutrients.

Medication use altering the gut flora balance.

The good news is - there's plenty of natural nutritious foods to support good gut health. They include:

Probiotics - including yoghurt, kimchi, kombucha, sauerkraut, kefir and pickled vegetables.

Prebiotic - including apples, pears, garlic, onions, leeks and leafy greens.

Amino acids - found in high protein foods such as meat, eggs, fish and beans.

Antioxidant and anti-inflammatory foods.

Allergens

There are many food groups that can be allergenic or cause intolerances. Many people cut out gluten, dairy, grains and/or sugar. This isn't necessarily bad in itself - but it can lead to nutrients imbalances.

Allergies and intolerances are thought to play a big role in autoimmune disease. Inflammation in the gut increases gut permeability, which allows more molecules through.

Many people with autoimmune conditions have multiple allergies and intolerances - it's a different fact of the same immune problem. Consuming foods that you're intolerant to can cause flare-ups in symptoms. But does that mean you should be eliminating foods?

Everyone will react differently to different foods - even if they have the same condition. So someone else's allergies won't necessarily match yours.

Elimination shouldn't be done without supervision and care. It's essential to monitor reactions and nutrient intake, otherwise the risk of too many exclusions and malnutrition is high. This is particularly true when it comes to conditions like Scleroderma, where malnutrition is already a likely problem.

The anti-inflammatory diet

There are many inflammatory factors in Scleroderma, so an anti-inflammatory protocol is often warranted.

This approach combines elements from different cultures, including Mediterranean and Asian. The foods used have anti-inflammatory, antioxidant and gut supportive properties.

For those with Scleroderma, an anti-inflammatory diet will help support healthy gut function as well and other common issues such as Raynaud's. It focuses on including nutritious foods, instead of just excluding foods, so it's nutrient-dense AND not mentally restrictive.

An anti-inflammatory diet includes:

Oily fish and other omega-3 sources
Colourful fruits and vegetables
Nuts and seeds
Olive oil
Green tea
Herbs and spices
Dark chocolate
Fermented foods
Broths

When it comes to holistic nutrition, the one outcome we want is to improve your quality of life and get you to the healthiest you can be.

If you would like some 1:1 nutrition support, Samantha has online appointments available. Simply email her to arrange a session or see www.samanthagemmell.com/general-serviced/ for more information.

Renal Crisis in Scleroderma Patients

by ANA PENA
Scleroderma News

High protein levels in the urine, poor kidney function, and high blood pressure at the time of systemic sclerosis (SSc) diagnosis are strong predictors for the future development of scleroderma renal crisis (SRC), a study suggests.

These and other laboratory findings can help identify those patients who are at a higher risk of renal crisis, allowing for early identification and timely therapeutic interventions, according to researchers.

The study, "Risk Factors for Future Scleroderma Renal Crisis at Systemic Sclerosis Diagnosis," was published in The Journal of Rheumatology.

SRC is one of the most serious complications of SSc. It affects 5 to 15 percent of patients, causing the abrupt onset of high blood pressure and acute kidney failure.

A few risk factors are known to predispose SSc patients to renal crisis, including exposure to corticosteroids, the presence of anti-RNA polymerase III antibodies, skin thickness, and significant tendon friction rubs.

Other conditions, such as high blood pressure, protein in the urine, anaemia, low platelet counts, and kidney disease, have been associated with renal crisis, but it is unknown if these risk factors are already present when scleroderma is first diagnosed.

To determine whether these clinical and lab parameters are predictors of future renal crisis at SSc diagnosis, researchers retrospectively compared data between SSc patients who later developed renal crisis and those who did not.

Patient data was derived from the military medical registry of the U.S. Department of Defence between 2005 and 2016. In total, researchers included 31 SSc patients who later developed renal crisis and 322 SSc patients without SRC, used as controls.

Results showed that, at the time of SSc diagnosis, patients who eventually developed renal crisis were more than 100 times more likely to have high protein in their urine, also known as proteinuria. Additionally, they had a 20-fold higher chance of having chronic kidney disease and a 13-fold higher chance of high blood pressure than those not affected by kidney failure.

Other risk factors significantly associated with renal crisis were anaemia, or low levels of red blood cells in the blood; an elevated erythrocyte sedimentation rate, indicative of inflammation; and low platelet counts, or thrombocytopenia.

Researchers also found that hypothyroidism, when the thyroid gland cannot produce enough thyroid hormone, also correlated with the development of renal crisis in SSc patients.

In addition, the presence of anti-RNA polymerase III antibodies and antinuclear antibodies in SSc patients was also associated with SRC development.

According to the team, displaying two or more of these risk factors at the time of SSc diagnosis predicted, with 94 per cent specificity, the eventual onset of renal crisis.

"Improved understanding of SRC risk factors at the time of SSc diagnosis could better instruct future clinical surveillance and prospective research," the researchers wrote.

The team also suggested that "this population may benefit from follow-up at closer intervals, more aggressive BP [blood pressure] monitoring, more stringent avoidance of steroids, and potential future therapies."

Researchers emphasized that studies on the use of angiotensin-converting enzyme, or ACE, inhibitors, angiotensin-receptor blockers, and calcium channel blockers before a renal crisis is diagnosed can improve our understanding of the benefits and potential risks of these therapies as preventive treatments.

Light therapy lamps could be 'game-changer'

Breakthrough for healing Digital Ulcers in SSc Patients

- by PATRICIA INACIO, PHD Scleroderma NEWS.

Light therapy delivered locally using a lamp that emits infrared, red and ultraviolet light reduced by 83 percent the burden of digital ulcers in systemic sclerosis (SSc) patients, a new study reports.

The study, "A feasibility study of a novel low-level light therapy for digital ulcers in systemic sclerosis," was published in the Journal of Dermatological Treatment.

Patients with SSc frequently develop digital ulcers, which are small sores that form on the fingers and toes as the result of impaired blood flow.

While several treatment strategies have been developed for this condition, "recurrent ulceration remains a major source of morbidity in some patients with SSc," researchers wrote. The use of vasodilators — such as , alosartan, diltiazem, nifedipine and iloprost — is a common therapeutic approach, although they are discontinued when poorly tolerated.

Therapies that act locally on digital ulcers skipping the systemic vasodilation are likely to be better tolerated.

Researchers at the University of Manchester and Salford Royal NHS Foundation Trust developed a low-level light therapy using a lamp that combines infrared, red and ultraviolet light to treat chronic digital ulcers.

An increasing number of studies have reported the positive effects of low-level light therapy in skin ulcers of diabetic patients. The light combination is thought to stimulate several processes; for example, the red and infrared light boost blood flow and with it the nutrients required for wound healing.

Moreover, infrared light — the same used in TV remote controls — increases the tissue's oxygenation, while red light enhances the body's antimicrobial defences. Red light also is reported to induce the deposition of collagen, the wounds' natural scaffolding.

Ultraviolet light — invisible to the naked eye — has an anti-bacterial effect and reduces inflammation, which acts against healing.

The new lamp developed by the team is composed of 32 different bulbs which emit infrared, red or ultraviolet light.

Researchers tested its effects in eight SSc patients who had a total of 14 ulcers. Treatment with the lamp was performed in 15-minute sessions, twice a week for three weeks. The majority of patients also were receiving treatment with vasodilatory agents.

Results showed that a total of 46 light treatments were administered successfully without raising any safety concerns. Moreover, the level of pain reported by the patients was low.

Importantly, after completion of the treatment, patients reported a reduction of 82.8 percent in digital ulcers' burden compared to the beginning (baseline) of the study.

Researchers used a second technique, called laser Doppler imaging, to measure digital ulcers healing. The technique was performed immediately before and after light exposures at the site of the digital ulcer. Results showed that following light therapy there was a significant increase in blood flow within the digital ulcers and in the surrounding tissue.

Currently, patients may receive light therapy at the hospital to treat ulcers, but this requires a period of five days of treatment and medications. However, the new lamp can be used at home.

"Ulcers cause much distress to patients — and current treatments are costly to the [National Health Service] and problematic for patients who can only receive them in hospital," Michael Hughes, University of Manchester, the study's first author said in a press release. "But this technology is cheap and practical — it's really a no brainer as it can be administered at home."

Moreover, the lamp may be adapted to allow clinicians to monitor patients' progress remotely.

"There are future possibilities," Hughes said. "We think this device could be easily adapted to monitor ulcers remotely using cameras. They could also be programmed to recognize different parts of the body so that the treatment is given accurately."

According to the Hughes, "this technology is a game changer; the implications are huge."

So far the results support the potential of the newly developed light therapy to treat SSc digital ulcers locally. Researchers now plan to test the new light therapy in diabetic ulcers, a common complication in patients with diabetes.

"In the next 6 to 12 months we shall be refining the machine and within 12 months we hope to [trying] it on diabetic ulcers," Hughes concluded.

Friends of Sclero
World Scleroderm

Scleroderma Victoria's World Scleroderma Day luncheon at The Grand Hotel in Richmond once again proved a huge success raising $7400 for scleroderma research.

A total of 68 guests enjoyed a special lunch of menu favorites served up by The Grand's award-winning Italian chefs.

Guests were welcomed by Scleroderma Australia President, Gene Swinstead and Amanda Lawrie-Jones, President of Scleroderma Victoria.

Special guest was the Ambassador to Scleroderma Victoria, Dyson Heppell. Dyson, captain of Essendon Football Club, recently shaved off his beard raising more than $62,000 for scleroderma research.

Committee member Louise Inglese gave a presentation on the role and value of Support Groups.

Scleroderma Victoria would like to thank the management of The Grand Hotel for their generous support of this event for the past four years. We are pleased to announce that they have booked us in for lunch on World Scleroderma Day 2019. Put June 29 next year in your diary.

We would also like to thank Flair Flowers and Design who once again donated some beautiful sunflower arrangements for our tables. If you need flowers call Flair. You will find them at 372 Burnley Street, Richmond.

Have a look at their website https://flairdesign.net.au/

Pictures show some of the The Grand lunch attendees.

oderma support
na Day fundraiser

Grand lunch for a grand day

Cold, tingling facts about Raynaud's

Now winter is upon us, the thermometer has dropped, and some people may feel it more than others – especially in their fingers and toes. That's because they may have a condition called Raynaud's disease (also called Raynaud's syndrome or phenomenon) that causes numbness in extremities when it gets colder.

While your fingers can go numb and change color in extreme cold for prolonged durations of time – commonly known as frostbite – those with Raynaud's can suffer uncomfortable symptoms even when the indoor or outdoor environment doesn't feel very cold to others.

Here are eight cold, tingling facts about this health problem...

1. White Fingers First

The Mayo Clinic explains that during an "attack" of Raynaud's, a patient's fingers usually turn white first (which is actually what happens during a more advanced stage of frostbite). The skin will then often turn blue, while feeling cold and numb.

As you warm and circulation improves, the affected areas may turn red, throb, tingle or swell." This is the opposite of frostbite, as the skin will turn red first before turning white – and defrosting from frostbite can also be quite painful.

2. Women are More Affected

According to Raynauds.org, women are more likely to have this health problem. It gets more specific than that – apparently women between the ages of 15 and 30 are most affected.

3. There are Two Types

The National Heart, Lung and Blood Institute explains there are primary and secondary Raynaud's, and that the latter version is actually more severe. The cause of primary Raynaud's isn't known, but it's more common.

Meanwhile, secondary Raynaud's is caused by an underlying health condition, such as those that affect the arteries or nerves associated with arteries in the hands and feet such as scleroderma.

4. Warm Water Rescue

Unlike frozen fingers (frostbite), dipping your hands in warm water when you have Raynaud's can provide some relief. Trying this with frostbite before circulation has returned can actually cause damage to tissue.

Another strategy if you're having a Raynaud's attack is to move your hands and feet to increase blood flow – "and to rub them where they are sore to help with circulation."

5. It Can Be Triggered by Stress

Cleveland Clinic explains that while cold is the biggest culprit when it comes to triggering a Raynaud's attack, it can also be brought on by emotional stress.

Whether it's from cold temperatures or stress, Raynaud's closes the blood vessels that supply the finger and toes more than the natural response should allow. Excitement can also lead to an attack, it adds.

6. It Affects More than Fingers

While the disease is most commonly associated with affecting the fingers and toes, Raynaud's can actually strike a number of other sensitive areas of the body.

Other areas of the body that can suffer during an attack include the nose, lips, and ears. Some women may experience Raynaud's of the nipples, which can be pronounced during breastfeeding and cause a lot of discomfort. "It causes severe throbbing, similar to that experienced with a fungal Candida albicans (C. albicans) infection, which can lead to misdiagnosis."

7. It Can be Triggered by Medications

NHS in the UK sys that secondary Raynaud's can actually be caused by certain medications – including certain types of anti-migraine medications such as umatriptan and ergotamine. Beta blockers used to control high blood pressure can also be a trigger, it adds.

The source continues by warning that certain decongestants and even birth control pills could be the cause of secondary Raynaud's. It's probably best to consult with a doctor to assess medications and see if any can be adjusted or changed to eliminate the problem.

8. There are Medical Treatments

While some medications may cause secondary Raynaud's, other drugs may help alleviate the issue, according to the Mayo Clinic. The source says your doctor may prescribe calcium channel blockers (including Afeditab CR or Procardia) to relax and open small blood vessels, while vasodilators including nitroglycerin cream can help.

Other sources say non-prescription pills, namely Vitamin B-3 pills (niacin), can help naturally increase blood flow and reduce the unpleasant symptoms of Raynaud's. It's always best to check with your doctor.

Save the date!

Our 2018 Annual General Meeting will be held on Saturday, November 24, in the meeting room, 11th floor, main building of St Vincent's Hospital in Fitzroy.

Financial members of Scleroderma Victoria, friends, family and carers are invited to attend (at no cost). There will be one guest speaker (to be announced closer to the date), tea, coffee and a light lunch will be served.

This is a great opportunity to hear the latest in research and meet your committee members and others with Scleroderma. Invitations will be sent out to our members closer to the date. We hope to see as many of our members there as possible, *save the date!*

Scleroderma will not take my smile

The Lupus, Scleroderma, Sjögren's Friendship Group (LSS) in Adelaide enjoyed a World Scleroderma Day lunch on June 29 going with the theme – Scleroderma Will Not Take My Smile!

The LSS Group had a great turn-out with a special scleroderma day cake and sunflower gloves worn by all. See photos above.

After lunch they took it in turns posing in a Scleroderma Will Not Take My Smile frame. The LSS Adelaide group meet regularly throughout the year. For information contact Pauline Sim at pauline_s@hotmail.com

New Support Groups

July saw two new Support Groups get together in Victoria.

First, six attendees (pictured right) braved the blustery conditions to meet others with scleroderma at the Geelong RSL.

New Group leader, Janelle Blight, chose the RSL due to its accessibility, ample parking and hearty meals.

The Geelong group are planning to meet on a monthly basis. Please contact Janelle Blight on 0413 046 110 or email dermageelong@gmail.com for more information.

Meanwhile Paul Hadfield got a group together at Ballarat. Although it was only a small group for their first meeting, it is hoped others will jump on board for future get togethers.

Paul can be contacted at paul.hadfield67@bigpond.com or 0484 342 925.

Donations to Scleroderma Victoria

All Souls Opportunity Shop
Pakenham CWA
Pethard Tarax Trust
UFS Pharmacy Bendigo
Uncle Jack Watches
Warranwood Primary School

Kathrin Allen
Rolf Bamert
Rebecca Banks
Margaret Barr
Gavin Birth
Maria Bonanno
John Bowles
Lloyd Bowman
Donna Bradley-Robinson
James Buhagiar
Jan Carmichael
Kingsley Carr
Anne Caruso
Robyn Cas
Margaret Casey
Debra Cass
Mason Chiodo
Tania Ciotti
Anne Clarke-Bowman
Jacoba Collins
Noella Costello
Bryan Craig

Amanda Cunninghame
Pina and Don D'Alessandro
Luisa D'Alessandro
Genevie D'Cruz
Dee Dinkgreve
Marie Dixon
Cherrill and Ray Earls
Jacqueline Edney
Joan Fisher
Stephanie Fong
Mazzi Geen
Margaret George
Barrie Gillespie
Tracy Godkin
Danni Gucciardo
Sheryl Haley
Timothy Harmer
Margaret Hayes
Roslyn Hill
Yvonne Hoffmann
Graham Howard
Carmela Inglese
Pam Jaremenko
Alison Jones
Belinda Jordan
William Joyce
Maurie Joyce
Mary-Ann Karm
Wayne Keast
Virginia Kenworthy
Dylan King

Connie Koger
Simon Kotanko
Jean Lapthorne
Sheryl Lewin
Judy Lightfoot
Jack Lightfoot
Sean Limbrey
Susan Macey
Charmaine McKendry
Barry and Heather Mills
Esha Mitchell
Margaret Morrow
Kylie Muller
Roslyn Munnecke
Peter Myers
Wendy O'Flaherty

Connie Petrou
Toni Pezzimenti
Glynis Phelan
Mary Pizzey
Moya Raleigh
Jane Rankin
Tom Robertson
Jacqueline Ross
Susan Roumani
Terry Ryan
Jill Sears
Sandra Simionato
Margaret Spargo
Lois Spear
Wendy Stanfield

Allan and Marlene Swinstead
Nola Tate
Romeo Toledo
Penelope Travis
Tom Velten
Jenifer Wallis
Barry Walters
Marjorie Ward
Sally Westbury
Ben Wharton
Lois White
Alana White
Gwenda Williams
Martin Williamson
Marliene Wise
Luke Zanier

FASHION PARADE

Don't miss our "More Than Skin Deep" Fashion Parade at the historic Collingwood Town Hall on Sunday, October 14.

Put it in your diary NOW and get a table of 10 together to join in the fun.

More Than Skin Deep
Fashion Parade Fundraising for scleroderma victoria

Study suggests -

Six-minute Walk test can predict prognosis of SSc patients

by Patricia Inacio, Phd

A lower score on the six-minute walk test (6MWT) correlates with disease severity and mortality in patients with systemic sclerosis (SSc), supporting its validity in assessing the prognosis of these patients, a study reports.

Results also showed that an additional meter walked during the test corresponded with a one per cent increase in survival.

The study, "Reproducibility and Utility of the 6-minute Walk Test in Systemic Sclerosis," was published in The Journal of Rheumatology.

The 6MWT is a safe, non-invasive test used to assess the exercise tolerance of patients diagnosed with chronic respiratory diseases, such as pulmonary fibrosis or pulmonary arterial hypertension, and heart failure. This test has also been increasingly used in patients with pulmonary hypertension associated with connective tissue disease, including SSc.

It measures the maximum distance an individual is able to walk over six minutes on a hard, flat surface. The person can walk at their own pace and can stop and rest as many times as they need.

In 2008, the test was recommended as a parameter in SSc clinical trials, but the number of studies that have actually assessed how 6MWT results correlate with patient's clinical outcomes is still limited.

Researchers have now conducted an observational study to evaluate the usefulness of the 6MWT in SSc patients.

The study, performed between 2002 and 2008, enrolled 56 SSc patients, 39 (70 per cent) of whom had diffuse cutaneous SSc. Most participants were females (68per cent), and their mean age was 46. Patients underwent at least two six-minute walk tests within a minimum three-month interval.

At each evaluation, researchers also analysed patients' clinical data, including body mass index and SSc subtype, among other parameters.

Three participants — 5.4 per cent — had SSc-related pulmonary arterial hypertension confirmed by right heart catheterization — the standard test to diagnose pulmonary hypertension.

At the first clinical visit, 31 patients had a normal six-minute walk distance (6MWD) value — a mean value of 524 meters — while the other 25 patients had abnormal, or lower, 6MWT results — an average of 373 meters.

Compared with SSc patients with normal 6MWD values, those with lower scores on their first clinical evaluation were an average of eight years younger — 49 versus 41 years old — and had significantly worse physical activity.

Additionally, they had higher muscle disease scores, more frequent pain in the joints, tendon friction, and higher impairments in lung function, measured by the forced vital capacity (FVC) and the diffusing capacity (DLCO) tests. FVC measures the amount of air that can be forcibly exhaled from the lungs after taking the deepest breath possible, while DLCO measures the ability of the lungs to transfer oxygen from the inhaled air to the blood.

The results suggest that absolute values of the 6MWD correlate with several clinical and functional outcomes of patients.

By the end of the follow-up period, eight patients had died — seven due to SSc, and one from both oesophagus cancer and liver cirrhosis. Six of these deaths occurred among patients with abnormal 6MWD values at first referral.

The researchers therefore suggested that 6MWT results are an independent predictor of mortality.

"The 6MWD absolute value at first referral was an independent predictor for both the overall mortality and SSc-related mortality," the researchers wrote.

They also found that one additional meter on the 6MWT was associated with a 1 per cent improvement in survival.

These results support the use of the 6MWT "as a valid tool to assess functional capacity, with a significant prognostic value at first evaluation but also during follow-up in SSc patients with various degrees of organ involvement," the team concluded.

World Congress examines new

Fifth Systemic Sclerosis World Congress, Bordeaux, France

The Fifth Systemic Sclerosis World congress was held in Bordeaux, France in February this year. Australia was well represented at the congress with eight Rheumatologists from Australia attending. Following is a report from those attendees.

Dr Laura Ross (St Vincent's Melbourne) presented two posters. The first on Echo findings in heart disease in Scleroderma, focused on the types and frequency of heart muscle involvement in Scleroderma.

The second poster detailed the role of inflammatory markers in the assessment of disease activity in Scleroderma.

Dr Kathleen Morrisroe (St Vincent's Melbourne) also presented two posters from her PhD work on quantifying the burden of Scleroderma.

The first poster looked at health related quality of life measures in a group of newly diagnosed patients with Scleroderma from five large Cohorts from across the world that form the Insync collaboration.

The second poster described the annual cost of care of scleroderma patients in Australia. This poster was nominated by Dr Dan Furst as one of the highlights of the meeting.

The outgoing chair of the Australian Scleroderma Interest Group, Associate Professor Susanna Proudman (Royal Adelaide Hospital), delivered an invited presentation entitled "Australian Scleroderma Cohort Study – recent achievements and future vision" in a session in which members from other internationally regarded registries presented updates on their registries.

The presentation focused on prize-winning research undertaken by ASIG fellow Dr Kathleen Morrisroe to quantify the "burden" of scleroderma, particularly due to pulmonary arterial hypertension (PAH).

First, she presented work on the value of early detection of PAH and then, the impact of PAH on patient's lives in terms of hospitalisations and visits to health practitioners including allied health professionals such as podiatrists, and loss of employment and work productivity.

ASIG's collaborations with other international research groups will permit further research in these areas to reduce disease impact and improve quality of life for people living with scleroderma.

Another presentation from a large international collaboration using DNA from nearly 10, 000 people with scleroderma, including patients in the Australian Scleroderma Cohort Study, described a "genome-wide" association study for uncovering genes associated with the risk of developing scleroderma.

This huge genetic study found 23 genetic regions associated with risk of scleroderma, 12 of which had never been described before and indicate new pathways not previously known to be involved in the development of scleroderma.

This study provides hope for developing new treatments for scleroderma directed at these pathways.

The SCOT trial of autologous stem cell transplantation (ASCT) in select patients with severe early diffuse scleroderma was published earlier this year. ASCT is a procedure where an individual's bone marrow is destroyed and replaced by the individual's own stem cells.

This trial showed some slightly improved clinical outcomes compared to 12 monthly infusions of cyclophosphamide (CYC) and has generated much interest in this novel therapeutic approach, as we await the emergence of new targeted drugs for this complex disease.

At the meeting Dr Shervin Assassi of Houston Texas, presented a sub-study from the SCOT trial evaluating the gene profile of 62 patients in the trial (27 receiving ASCT and 35 receiving CYC) at pre-treatment baseline, 8 and 26 months, and 62 age- and gender-matched controls at similar time points.

Dr Assassi and colleagues showed two distinct 'molecular signatures' (interferon and neutrophil modules) in the scleroderma patients, not found in the controls. Moreover, they showed that these signatures are returned to near-normal state in those receiving the stem cell transplant compared with those receiving CYC.

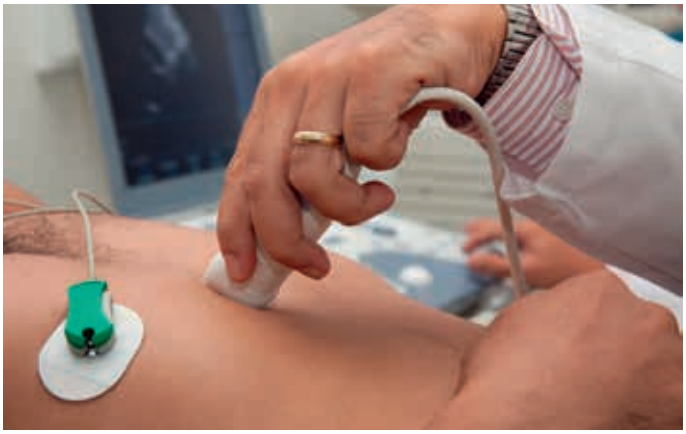
The implications of this study are two-fold. Firstly, they confirm that ASCT 're-sets' the bone marrow of affected individuals, from which the disease process may arise. Of course, until long-term follow-up studies are performed, it is not known how long this effect will last.

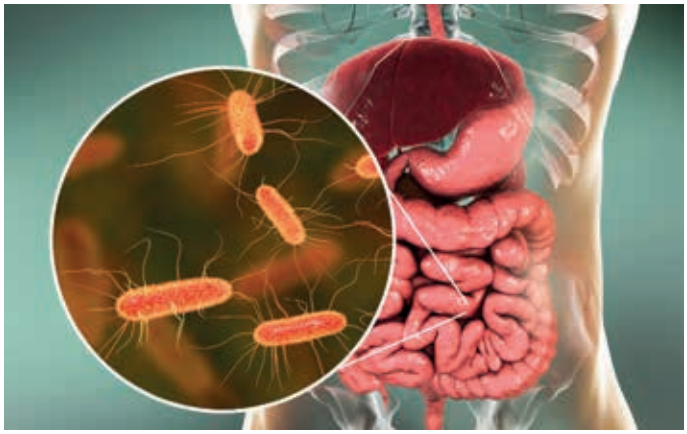
Secondly, and perhaps more importantly, the identification of molecular signatures in scleroderma enhances our understanding of the disease process and what genes (and proteins produced by those genes) could be targets for the development of new drugs for scleroderma.

It should be emphasized that ASCT is not for all scleroderma patients and that only a very small number of carefully selected people are likely to have a benefit that outweighs the potential risks which include severe infections in the phase before bone marrow regrows, which can result in death.

There is much that we need to learn about the role of ASCT in scleroderma, including which patients stand to benefit most, and how to perform the procedure in the safest and most effective way.

scleroderma research





Another interesting presentation was on the gut Microbiome in Scleroderma. There is a growing body of evidence that supports the suggestion that there is a relationship between the organisms that live inside the gut ('microbiota'), the host's immune responses and the development of various autoimmune diseases including scleroderma. In a study presented by Dr Natallelo of Rome Italy, based on analysis ('RNA sequencing') of stool specimens, patients with scleroderma had a distinctly different composition of microbiota compared with healthy individuals without Scleroderma.

In general people with scleroderma had an imbalance of healthy versus "bad" bacteria. This finding was seen particularly in those with more diffuse skin involvement. These findings raise the possibility that restoring gut equilibrium may be a therapeutic strategy worth exploring in scleroderma.

Two oral presentations at the congress presented new insights into scleroderma-associated heart muscle disease (cardiac disease).

The diagnosis of cardiac disease presents a significant challenge to clinicians as there are few tests that are adequately sensitive to detect early changes of cardiac disease, prior to the onset of symptoms such as breathlessness and altered heart rhythm. Additionally, there is little long-term data available to understand the meaning of abnormal findings of advanced investigation techniques such as cardiac MRI.

A Dutch group of researchers performed an echocardiography study of 408 patients and showed that a novel echocardiography measurement of left ventricular function is a better measure of cardiac involvement than current standard echocardiography measures.

Impaired global longitudinal strain, an assessment of how effectively the left ventricle is contracting in each heartbeat, was associated with a higher number of heart symptoms and cardiac events, suggesting this might be a good method to use when looking for heart muscle disease.

Other factors found to be associated with development of cardiac disease were increased NT-proBNP levels, a blood test indicating impaired contraction of the heart, and reduced diffusing capacity of the lungs, measured on respiratory function tests.

A multi-centre cardiac MRI study of 150 patients examined the association between MRI evidence of cardiac inflammation and fibrosis and arrhythmias. All patients enrolled in this study had a history of cardiac arrhythmia (irregular heartbeats) and the authors found that inflammation and fibrosis on MRI strongly predicted the presence of heart rhythm disturbances.

Seventy patients in this study had clinical follow up six months after their MRI. Fibrosis detected on MRI was a better predictor of patients who would go on to experience heart rhythm problems than assessment with a 24-hour Holter monitor test, the test that is currently most commonly used to assess for cardiac arrhythmias.

These studies are important as they offer insights into how we may begin to be able to detect patients with scleroderma cardiac disease, prior to the onset of symptoms. This potentially offers a 'therapeutic window' to institute treatments that may improve patient outcomes as current therapies for symptomatic cardiac disease are limited.

We have summarized just a few of the many presentations from the three-day meeting. There were over 1000 attendees at the meeting and over 380 posters submitted to the conference.

The conference is held every two years and the number of attendees and increasing number of papers submitted each year indicates the increasing research that is being done into so many aspects of the disease and provides hope for future treatments.

My Mum, a true inspiration

A daughter's tribute to her mother

Dianne Orton 25.5.49 - 26.2.18

"Dianne was a true inspiration to those around her, maintaining positivity and courage, even in the difficult end stages of her life..."

My beautiful Mum Dianne was diagnosed with limited scleroderma in 2006 at the age of 57.

Finding a reason for her stiff joints and tight skin was of some comfort to Mum and she did everything she could to assist her body to cope with the diagnosis.

Wanting to help others with scleroderma, Dianne became part of the research group at Monash Medical Centre (Melbourne) where she underwent health checks every three months. This included regular lung function tests, heart checks and general health assessments.

Dianne never smoked, was quite the teetotaller and ate a healthy diet. She loved to play golf and go for walks but these activities slowed down as they became more difficult for her.

Along with many others who have scleroderma, Dianne suffered from severe Raynaud's syndrome. Her hands became so swollen and blistered during winter she could not use them without experiencing intense pain.

Her legs were also swollen with oedema and her joints so stiff all movement was difficult. Over the past few years Mum had also lost a lot of weight. She felt that something was not right, but despite numerous blood tests and medical appointments, nothing was found.

In October 2017 Dianne moved up to Northern NSW to be closer to family. Her hands improved dramatically with the warmer weather.

However, daily life was a challenge. Stiff joints became stiffer and walking any distance was proving very difficult. But Dianne kept going about her business as best as she could.

Early 2018, after being assessed by a rheumatologist and cardiologist in northern NSW and sent for blood tests followed by an ultrasound and CT scan, cancer was discovered in the lungs, liver and bones, thought to have begun in the lungs.

We were told that Dianne had very little time to live so made the absolute most of the time we were given.

The positivity and courage displayed by Dianne throughout her final weeks was not just admirable but truly inspirational. She comforted me when we were given the news about her cancer, supported friends who were going through difficult emotional situations and continued to help everyone around her.

Mum had said that when she can no longer assist others, it will be time for her to move on to the next chapter of her journey and that is what she did.

Mum died with utmost dignity, finding the good in every day and accepting life as it was.

One thing I have learned is that if you feel something is not right, continue to investigate.

This is crucial for those with a compromised immune system as research has shown that some patients with scleroderma are more susceptible to developing cancer.

We miss you every day Mum.

Your memory lives on through family and all of the lives you have touched.

Your loving daughter

ELISE xx

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
Vice President: Belinda McMaster
Secretary and Operations Manager: Jennene Caton E: jennene14@gmail.com
Treasurer: Iain Pizzey E: cpizzey@tpg.com.au

COMMITTEE MEMBERS

Judy Browning
Bruce Manion
Gene Swinstead
Jane Rhyder
Sally Westbury
Louise Inglese

NEWSLETTER EDITOR

Gene Swinstead
E: geneswin@gmail.com

VICTORIAN SUPPORT GROUPS

Co-ordinator - Judy Browning (Bendigo)
E: judybrowning2@bigpond.com (03 5437 3305)

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
Annette Gaiardo PM Online Group
15 Nursery Lane, Tooradin 3989 (5998 3553)

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).

TASMANIA

Hobart Sally Westbury E: sally@westbury.name (0414096881)

Contacts but no support group –

Margery Cairns E: Geelongmjcairns22@gmail.com
Cheryl Rosini - Maryborough: 03 5461 1356
Sharon Egberts - Mildura 5024 2337
E: shajoy54@gmail.com
Launceston - Margaret Murray 6391 8561