scleroderma victoria

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NEWSLETTER SUMMER 2020

EDITION 152

Brave Mr H honoured at our AGM

Scleroderma Victoria has announced its sponsorship of the Harrison Pennicott PhD scholarship in collaboration with the University of Melbourne.

The announcement was made by President Amanda Lawrie-Jones at Scleroderma Victoria's recent Biannual Conference and AGM.

The scholarship is named after brave young Harrison Pennicott (Mr H) who has been battling Scleroderma for more than two years. (See story on Page 5).

Inspired by young Mr H's fight and the fund-raising efforts of his family and friends, including our Scleroderma Victoria Ambassador Dyson Heppell, Scleroderma Victoria's committee voted unanimously to fund the PhD program for the purpose of one or more scholarships for PhD students to conduct research into systemic sclerosis (Scleroderma).

Over the next three and a half years, we will donate $30,000 per annum to ensure the important research that Dr Mandana Nikpour and the Australian Scleroderma Interest Group (ASIG) team is continued and supported.

ASIG is recognised world-wide as being at the forefront in Scleroderma research.

Harrison Pennicott and his family were honoured to receive the naming title of the Scholarship, knowing their fund-raising efforts were creating a long-lasting program to benefit the Scleroderma community.

Harrison, flanked by his brother Miller and mother Leesa.

Great year for Scleroderma Victoria

Scleroderma Victoria had another good year in 2019, recording a surplus of $59,415, up $19,729 on the previous year.

The result was mainly due to the increase in publicity generated by Dyson Heppell, our Ambassador for Scleroderma Victoria.

His role significantly increased our media exposure on TV and in newspapers which, when linked with World Scleroderma Day on June 29, resulted in an increase in donations to the foundation.

Our More Than Skin Deep Fashion Parade at the Collingwood Town Hall raised $21,301 and our World Scleroderma Day luncheon at The Grand Hotel in Richmond contributed $6855.

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Stellar year for Scleroderma Victoria

FROM THE PRESIDENT
Amanda Lawrie-Jones

It was another stellar year for Scleroderma Victoria, and I would like to congratulate our amazing volunteer committee in all of their efforts once again to make it a successful year.

We recognised our 40th year in many ways and sought out past members to acknowledge their contributions and stories from the past.

It was also a year of change with a new mailing address and phone number in place, as well as moving along with the times in setting up new technology to assist us in our operations.

If you take a look at our website and peruse the Bios of our outstanding committee members, you will see new ways to contact us to ensure we create that extra personal touch with our Scleroderma community and members.

Change for Scleroderma (C4S) continued enabling you to contribute in your own home without doing anything strenuous to help us raise funds and awareness.

So far, this campaign has brought in $782 in funding which goes towards our new flyers and brochures for awareness and support.

A new membership flyer has been created and we kicked off another campaign to align with our 40th anniversary called #Target400. The new logo and campaign aimed to increase our membership base to 400 to help us grow our support group networks.

We started 2019 with 270 members, and we are now at 307 and hope to reach our #Target400 by the end of the financial year. We look forward to welcoming you as a new member very soon!

As always, the 2018 AGM was highly successful, with Dr Wendy Stevens providing a great talk on Scleroderma and burden of cost to our health system. We had lots of old and new faces in the room and thank you all for making it a great day.

World Scleroderma Day at The Grand Hotel in Richmond on June 29 was another great success. As always, our Committee put together a fun and informative event and I'd like to thank all who helped out!

Dr Wendy Stevens presented and our donations for the day were also up from last year with the total raised coming to $6855.

This year brought us some new connections and opportunities, where we renewed a valuable relationship with Actelion. This has not only helped Scleroderma Victoria but has established great connections and collaboration across other States, providing informative and important ways to increase awareness of Scleroderma across the country.

Actelion also provided part funding for myself to attend the 2019 National Patient Education Conference in Chicago for the second year in a row.

This year it was held in Chicago, and as the 21st year for the Foundation the focus was on the boundless optimism and relentlessly positive spirit of people with scleroderma and their family and friends.

One of the most notable and exciting moments was the first presentation for the day on Lung involvement in Scleroderma where ASIG (Australian Scleroderma Interest Group) was mentioned as a leader in the Screening Protocol for PAH (Pulmonary Arterial Hypertension).

Our two regular and ongoing supporters of Shirley's Knits and the Monash Stall still provide us with some fantastic opportunities to raise funds and awareness with new and different people. Shirley loves to 'click and clack' with her knitting needles at many events and functions and has sold over 40 scarves this year with a total contribution of over $1200. Our June Monash stall raised $514 and we would like to thank all of our volunteers, including; Margaret, Christina, Lynette and Libby, Emily and Bruce. Thank you also to everyone who made goods to sell.

Scleroderma Victoria's third More Than Skin Deep Fashion Parade held on October 20 at Collingwood Town Hall was one of our biggest and best ones yet.

This year the Parade showcased Australian Designers of women's and men's fashion.

The incredible designers included Jimmy Fox, Mr Robinson, Orocéo Castro, Nevada Duffy, Mazi, Kwacha Fashion, Iva Pfeiffer Creations, and Lady of Leisure Millinery. The live music was supplied by ELISHA and as always, the traditional live Auction with an assortment of wonderful prizes and experiences was great fun with Paul Richards from Bekdon Richards Real Estate. Our famous 'Lucky Bag' raffle was yet again a great success.

At the end of a wonderful and fun day, we raised $21,301.

We were also pleased to announce a significant new opportunity for our members with Scleroderma to have access to the Oral Clinic at Royal Melbourne Hospital.

The Oral Medicine Department at The Royal Dental Hospital of Melbourne is an initiated pathway for individuals with Scleroderma to be assessed for oral manifestations associated with their diagnosis.

Oral Medicine is a specialty which diagnoses and manages oral skin diseases and non-tooth related pain syndromes of the mouth and jaws where some individuals experience a narrowing of their mouth (microstomia) or changes in salivary flow.

We are incredibly proud to have been able to share and acknowledge our 40th anniversary with our members and the Scleroderma community in 2019.

Our President, Amanda Lawrie-Jones, takes a look at the past year, our bi-annual conference and what lies ahead in 2020.

Bring on 2020

Time flies when you are having fun! 2019 came and went in a flash, but again we are proud to say that we had another successful year.

Our 40 th anniversary year was filled with great events such as our regular World Scleroderma Day Lunch at the Grand Hotel in Richmond, our Monash Fund-raising Stalls and our More Than Skin Deep Fashion Parade.

Even though our Conference is held Bi-annually, we were pleased to have this one even bigger and better than past events. With the help of an RACV Grant, we were able to change venues to somewhere with improved accessibility.

We kept our 40th anniversary theme going, and as always it was a very successful and informative day!

Dr Jo Sahhar spoke about where we have come in the past 40 years. She acknowledged the important journey Scleroderma Victoria has played as well as supporting the Australian Scleroderma Interest Group (ASIG) in their significant research and collaboration to improve the lives of people with Scleroderma and our community.

Dr Wendy Stevens was fresh off a plane from the American College of Rheumatology Conference in the United States, sharing with us the latest information and Research. Dr Stevens also highlighted our local contribution to Scleroderma Research, with plenty to be positive about for our future.

As a Committee, this year we worked hard to reach out to a selection of different speakers and presenters, to ensure we covered things that are sometimes missed in Scleroderma discussions.

Dr Jason Teh provided some great in-'sight' (pardon the pun!) on Scleroderma and dry eyes.

He brought along with him a tool to assess and view people's eyes and provided many hints and tips on how we should be taking extra care of them.

Dr Tami Yap is part of the Royal Dental Hospital in Carlton that runs the Oral Dental service for patients with Scleroderma. Dr Yap provided some great advice on how we can take care of the health of our teeth, gums, and the entire oral-facial system that allows us to smile, speak, and chew with the complexities of Scleroderma Microstomia.

Kate Smythe shared with us her story of hard work, determination and the rise and fall of becoming an elite athlete and Olympian whilst overcoming many life challenges. The motivational aspects of her talk were encouraging and provided us with a sense of hope on overcoming adversity.

For many of us, and especially if you have Scleroderma, we know that it is important to maintain physical activity to manage our muscle, bone and joint health.

Carolyn Page is a Senior Physiotherapist from St Vincent's Hospital who presented on helpful tips to keep us all moving whilst managing fatigue.

As you can see, the AGM / Conference was jam-packed! And yet, that is not all.

We also had the opportunity for our extraordinary Committee to share all of our happenings over the past 12 months and announced our incredible new initiative with the 'Harrison Pennicott PhD Scholarship' which you can read more about on page 1.

All of our Committee members were re-elected for the following year, so no doubt we will continue to work hard as a collaborative team to bring the very best support we can provide.

But remember, we can't do it without your support.

As part of our 40 th anniversary year, we are very grateful to our new members in helping us with our #Target400 campaign. We will keep aiming for our target of 400 members and hope you can help us to continue this campaign. Keep sharing with your friends, family and colleagues to promote what we do, and why being a member is important to the continuance of our work.

To all our members new and old, we appreciate your support as your membership fees go towards our administrative costs to ensure we can deliver meaningful outcomes for people with scleroderma in our community.

Once again, our More Than Skin Deep Fashion Parade was a huge success! Our Volunteer Committee did a great job in pulling this off and I would like to give a special call out to Louise Inglese!

This has become her annual project event, and each year it becomes bigger and better.

There were a lot of volunteers for the day, including our models, makeup artists and other staff that all worked collaboratively to make the day a huge success. If you attended, I hope you had a great time and make sure you #SpreadTheWord and bring along more family and friends next year!

In wearing both hats of Scleroderma Victoria and Scleroderma Australia, I have had the opportunity in my travels to meet with some of our other State Committee members to increase support across the country.

Wendy Smith who is our Western Australia committee member, Marilyn Singer who is the President of the NSW committee, Cheyenne McLeod, Gordon Harris and Don Noone from Queensland, as well as Dylan King who is the new representative for South Australia.

Our 40 th anniversary year has been one to remember, filled with uplifting events and awareness for us at Scleroderma Victoria. We hope you had a great time if you attended any of our events and we hope to see you at one of, if not all, of our next events in 2020.

Scleroderma heart study

Our Secretary; Jennene Caton, recently took part in a research study examining heart involvement in Scleroderma.

This study is being conducted by Dr Laura Ross as part of her PhD with the University of Melbourne. The title of the study is "Breathlessness in systemic sclerosis – quantifying the contribution of cardiac fibrosis".

The aims of this study are to:

- Define the extent of heart inflammation and fibrosis present in individuals affected by scleroderma using cardiac MRI.
- Measure the exercise capacity of individuals with scleroderma using cardiopulmonary exercise testing in order to evaluate a possible link between heart fibrosis and reduced exercise capacity.

Jennene attended the Baker Heart and Diabetes Institute in Melbourne where several tests were conducted. Firstly, Jennene participated in a cardiopulmonary exercise test (CPET) where her capacity to exercise was measured whilst riding a stationary bike for 12 minutes. This was followed by a 90 minute MRI where detailed images of her heart were taken. Finally, Jennene was sent home wearing a heart monitoring device to for 24 hours.

At the completion of the study Jennene said that she was pleasantly surprised that she was able to complete 12 minutes on the stationary bike. "The resistance kept increasing throughout the 12 minutes, so I treated it like an Olympic event!" That's just as well, because she has to go back and do it all over again in 12 months' time.

This research study has been made possible via several grants, including one for $25,000 from Scleroderma Victoria. At the completion of her study, Dr Ross will be invited to share her findings with us, hopefully at our conference in 2021.

Only 40 participants are required for this study, several of our members are already involved.

Criteria is aged less than 70, Scleroderma for less than four years or more than 10 and no history of heart disease.

If you would like to be a participant, please contact Dr Laura Ross directly; *laura.ross@svhm.org.au*

Our Secretary, Jennene Caton, gets on her bike in the aid of science.

Health Smart Pharmacy

HealthSmart Pharmacy® was formed in 2008, with one of the co-founders being Joseph Tesoriero (pictured above).

Joseph has long supported all patients being a Pharmacist, and this includes many people with Scleroderma.

In 2017, Joseph and HealthSmart were generous in supporting Scleroderma Victoria with free samples to fill up our 'Goodie bags' for our Bi-Annual conference, as well as a donation of $500 to go towards the catering for the function.

This year, they have once again contributed to our 'Goodie-bags' and increased their support to a significant amount of $5000. We are very grateful to HealthSmart and their continued support.

Joseph has shared with us a little about why he became a Pharmacist, and his involvement with Scleroderma.

Why did you become a pharmacist?

When I was young, I wanted to be a lolly-pop man and give lollies to everyone to make them happy. In effect, being a Pharmacist is kind of the same thing.

If I wasn't a pharmacist, I would have been a comedian or an actor. I like to entertain people. But I think I chose the right path.

What interests you in helping people?

Generosity. It's an interesting topic. I'm a treasurer for a church and have been for over 20 years. Recently I gave a sermon on generosity and the impact it can have on others, as well as yourself. You enrich yourself as you pour out yourself to help others.

I am proud of the HealthSmart group of pharmacies that I co-founded over 10 years ago. It has given me opportunities that I could not have dreamed of, and now gives me opportunities to assist others where I can.

What is your favorite thing to do outside of work?

I have a wife and two adult children (Helen with Gabbi & Matt) who are the world to me. As does following the St Kilda football club, which has taught me a lot about humility and patience. (and sadness & despair)

What is the thing you have learnt about Scleroderma that surprised you the most?

I was recently really surprised at how long It took someone who has scleroderma to heal from a skin wound. It was so long it must have been so frustrating.

HealthSmart Pharmacy's vision was to be the premier provider of Community Pharmacy services in public hospitals in Melbourne, and over the years they have expanded their pharmacies across the State of Victoria. You can find out about their locations on their website - Live Health Smart.

As well as being treasurer for the church, I am Treasurer for their café (Steeple Espresso Bar & Deli), their mobile coffee van (www.steeple.coffee) and Prepped Smart & Healthy (www.prepped-smart-healthy.org).

The brave journey of Mr H

Through various forms of media, we have all been following the brave journey of young Harrison Pennicott's battle with Scleroderma.

We have read about his triumphs and his setbacks. We've watched his fund-raising activities. We've seen the special bond he has formed with Scleroderma Victoria's Ambassador Dyson Heppell, Captain of Essendon Football Club.

We've seen the massive support Harrison has received from the Team Harrison group and the unending backing he has had from his school.

Harrison, who likes to be called Mr H, has been in the daily newspapers. He's been on television.

But what about the brave family behind him? How have they coped with the unending medical problems that keep getting thrown up?

In this article, his mother Leesa, tells of his struggle and some of the decisions the family has had to make leading up to and going through with Mr H's stem cell transplant.

Leesa's story is below.

Mr H putting in a Christmas request.

Harrison's Stem Cell Transplant

Autologous V Allogenic

Harrison had been battling Scleroderma for nearly two years and as much as our medical team had searched far and wide for a way to stop the progression of this insidious disease, unfortunately nothing was successful to date.

I clearly remember the day Harrison's Dad, Jamie and I were ushered into a meeting room at Royal Children's Hospital Melbourne where our team advised us that they had exhausted all conventional treatments and if we left Harrison the way he is he will end up in a wheel chair and his life expectancy was short.

The team included Francoise head of Oncology at Royal Children's Hospital and an expert in Bone Marrow Transplants. She explained to us that the only option left was a Stem Cell Transplant and she believed this was the solution for us – in her words "I'm here to Cure him".

There are two types of transplants Autologous (own cells) & Allogenic (donor) and the risk involved for both of those were explained and we were to make the final decision.

Jamie and I were on the same page and there was no other answer than Yes we need to do this, not only for Harrison, but our whole family, we decided on Autologous Transplant.

There is bit of a process to harvest your cells from your body which includes medication to grow extra cells, insertion of a line into your groin to harvest them out (Hickman line) and testing to be done. It was a very successful harvest and Harrison's battered body produced a record number of cells.

On September 25, 2018 Harrison lost his first tooth and got his stem cells back, it was an exciting day. However, we were very nervous about the risks involved which can include visits to ICU and the risk of dying.

Every day I would wake up and hear a beautiful voice "Good Morning Mum How are you?" Harrison was so brave, strong, he ate throughout the whole transplant, he didn't need any visits to ICU or a Nasal Gastric tube and at day +20 we were discharged from hospital with the weight on our shoulders to keep him healthy, happy and fingers crossed this was the answer for Harrison.

We had survived 29 days in hospital, and I couldn't believe we had done it. Not only had we done the hard yards, but we held our heads up high, Harrison was such a happy soul throughout the process, he rarely complained – it was like he knew what we were doing here was the only way too.

As the weeks and months went on, we had a few minor scares, but everything was managed perfectly by Francoise.

As a precaution we all undertook tissue sampling to see if any of us were capable donors, just in case it might be needed down the track. If we weren't suitable, our beautiful friends were lined up ready to get tested.

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Harrison & Francoise created such a beautiful bond and we were heartbroken to hear she was moving back to France. She taught Mr H some French and wanted him to visit her in France to eat Croissants. H nicknamed her Dr Painwise and my worst enemy (because she wouldn't let him do anything he wanted to) all in good spirits. To this day she keeps in contact with H's current Dr and misses him dearly.

As we were seeing improvement in his mobility and skin, it was a false sense of reality, the reason behind the improvement was because he still had no immune system, so his body was "healthy as such".

In February 2019 we hadn't seen Harrison this happy and moving so well in over two years and we honestly thought that a miracle had happened, how wrong were we.

Our medical team decided we needed to wean Harrison off Steroids' to get the T Cells (immune system) back functioning in his body to see if this transplant was successful or not – it didn't take long for our worst nightmare to come true.

It took around four weeks for Scleroderma to take over his body again dropping 2 kilos, not eating, in pain again. Our hearts were shattered, and it still makes me so sad today that we had to do this all over again – what a waste of six months.

But we were prepared, and Mr H's brother Miller was up now. It's difficult putting so much pressure on your child and I had to explain to him that he was giving Harrison a gift, it was up to the doctors/nurses to make sure it works and he had done everything he could to help his brother.

We were once again told the risks but this time they were much higher – it was a 1 in 5 chance of mortality, visits to ICU, this was different to the last one they kept telling us, he will struggle everything is different.

Once again Harrison's strength, positivity and resilience shone through, he surprised everyone including his new doctor Dave, but for some reason I wasn't surprised, Harrison was different, even though he was sick on the outside he was super healthy on the inside, we were proving them wrong and once again I was right.

From day +21 you start getting your immune system back and like clockwork this happened and all of a sudden, we were told day 30 you will go home, so start planning, We were so excited but it was short lived.

Harrison all of a sudden stopped eating and was just flat, his doctor was very concerned with his fingers and we found our Harrison has staph, antiobiotics, nasal gastric tube inserted, he was in so much pain we increased his pain meds and ended up putting him on Ketamine.

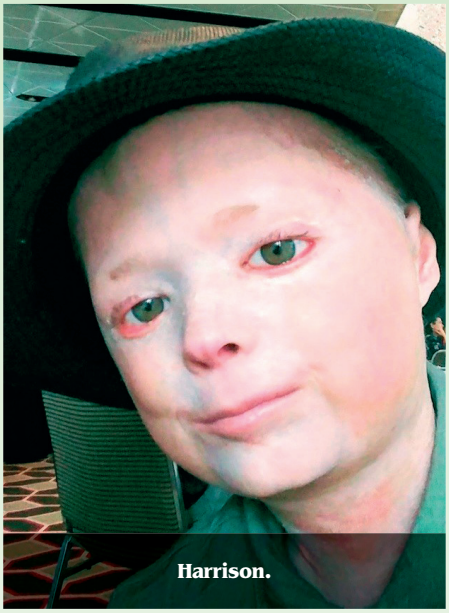
Harrison's journey hasn't been an easy road for him, us or those close to him, seeing him change so much is heart breaking. He misses out on so many things in life like swimming lessons, school, playing sports with his mates, being a boy because boys are rough, playing football with his best mate Dyson. But through all of this Harrison has always seen the good side of life, he is happy, cheeky, positive and has the best sense of humour.

We are forever grateful for the support we have received from the very beginning in 2016 until today. It truly has been heart-warming to know there are still so many good people in the world, including people who have known us for 20 years, to complete strangers who have read Harrison's story online.

In 2018 we achieved a lot. Harrison got an aide for school, we were approved for NDIS, we were on the Good Friday Appeal, in the local newspaper, Get Behind the Beard and raised much needed funds for research. The most important part was getting the word Scleroderma out there.

If there is anything we want to take from this journey of ours it that we hope Harrison's story is an inspiration to others to never, ever give up . . .

Harrison and best mate Dyson.



Harrison.

Journey continues

Mr H Update – Day 163 – It's almost six months post-transplant and every day we are seeing more and more improvement in walking, talking, stamina and overall health.

Unfortunately, late Sunday night we had a trip to the Emergency Department - the Hickman line as well as the cuff had started to come out which means it could fall out. They did think infection, but bloods or swabs never came up with anything, a few days of antis and H is jumping out of his skin again.

One of the biggest things we have noticed is that last transplant he never really got better at all, everything about this transplant has been so different and much more positive - we are so excited to see what the next six months brings.

The only battle we have is the damage to his hands, especially his fingers. This month H will undertake surgery to remove his little finger on the left and fuse his index finger on the right in the hope we can try and save it, especially for functionality for the rest of his life as well as the ability to play sport, even catch a ball!

Mr H finished school for the year on December 20. His classmates who have supported, accepted and followed his journey, embraced him, and totally understood what he went through. I like to think H had taught them to be grateful for a healthy, happy life, accept people for who they are and to always smile. We can't thank his beautiful teacher Ashleigh Franklin enough for her care and love this year also! Bring on 2020 filled with love, health and many happy memories! As always thanks to our amazing support network we love you all!

- Leesa Pennicott

Patient-reported symptoms may reflect changes in SSc activity

by Marta Figueiredo, Scleroderma News

Patient-reported symptoms — specifically those related to blood vessel, skin, and lung function — may be used to indicate changes in disease activity in people with systemic sclerosis (SSc), an Australian study suggests.
The study, "Can patient-reported symptoms be used to measure disease activity in systemic sclerosis?," was published in the journal Arthritis Care & Research.

Systemic sclerosis, or scleroderma, affects multiple systems and almost any organ in the body, causing progressive, widespread fibrosis (tissue scarring). Besides its hallmark affected organ, the skin, the disease commonly affects the heart and blood vessels, the lungs, stomach, and kidneys.

Quantifying disease activity in scleroderma patients remains challenging because of its complex cause and development, the episodic nature of certain symptoms, and the lack of validated biomarkers or objective measures for the various aspects of disease activity.

To overcome the lack of objective measures to determine disease activity in all organs, patient-reported symptoms and assessments have been included in disease activity indices and outcome measures. Other situations where patient-reported symptoms could be relevant for the assessment of scleroderma are at a first clinical visit or when scheduled tests have been missed.

However, the relationship between patient-reported symptoms and objective features of scleroderma disease activity remains unclear.

Researchers set out to evaluate the association between patient-reported symptoms — specifically Raynaud's phenomenon, skin manifestations, and shortness of breath — and objective measures of scleroderma disease activity.

Raynaud's phenomenon (a condition that affects the blood vessels in the fingers and toes, making them numb, prickly, and frigid in response to cold temperatures or stress) and skin manifestations are among the most common and early symptoms of scleroderma. Shortness of breath is considered an important predictor of fibrosis-associated lung diseases and death from heart-associated conditions.

These symptoms have been previously suggested to correlate, at least to some degree, with objective measures of disease activity.

The team analysed data collected from 1636 adults with scleroderma enrolled in the Australian Scleroderma Cohort Study (ASCS), a prospective multi-center study assessing risk and prognostic factors in scleroderma.

Participants had a mean age of 57.37 years, 86 per cent of them were women, and 25.73 per cent had diffuse cutaneous scleroderma. At enrolment, they had a mean disease duration of 11.07 years, and were followed for a mean 3.99 years.

At each annual visit, they were asked if their Raynaud's phenomenon, skin manifestations, or shortness of breath had been worse in the preceding month, and objective features of disease activity were used to assess the corresponding affected organ. The research team evaluated the presence of digital ulcers and new digital pitting scars (blood-vessel related); changes in modified Rodnan skin score (mRSS), which measures skin thickening; new areas of skin scarring, new-onset joint contractures (skin-related), plus changes in lung function tests, new-onset interstitial lung disease (ILD), and new-onset pulmonary arterial hypertension (PAH) (lung-related).

Results showed a significant association between patient-reported worsening Raynaud's phenomenon and the presence of digital ulcers. In addition, patient-reported worsening skin manifestations were linked to increasing mRSS scores, while patient-reported worsening in shortness of breath was associated with deterioration of lung function tests, new-onset ILD, and new-onset PAH.

Patients with worse Raynaud's phenomenon symptoms within the preceding month were 53 per cent more likely to have digital ulcers, while those reporting worsening skin manifestations had twice the risk of skin disease.

"Despite the multi-factorial nature of the patient experience of breathlessness, there remains a strong relationship between patient-reported worsening breathlessness and clinically meaningful change in [lung function tests] and pulmonary dysfunction in SSc," the researchers said.

The most noticeable association in lung-related function was found in patients reporting increased shortness of breath in the preceding month, who were five times more likely to be diagnosed with PAH.

Supported by these findings, the team believes that "patient-reported symptoms are associated with clinically meaningful changes in disease activity in SSc patients," and "when objective measures of change in disease status are unavailable, patient-reported symptoms could be used to indicate a change in SSc disease activity."

Get your IBS under control in 2020

Are you a patient suffering IBS and wanting to learn more about the three step FODMAP diet?

If so, the expert team at Monash University has developed an online course to help you better understand your condition and how to safely follow a three step FODMAP diet.

The five-module course is written with patients in mind, so there's no jargon or complex language. We simply teach you in plain English about everything you need to know to understand your condition and to manage your symptoms using a FODMAP diet.

The course covers all the essential topics including:

- The importance of getting an accurate diagnosis of IBS
- What are FODMAPs and where are they found?
- What is the FODMAP diet
- How to implement Steps 1, 2 and 3 of the FODMAP diet
- Understanding whether your IBS symptoms are sensitive to FODMAPs
- What to do if your IBS symptoms do not improve on a low FODMAP diet
- Other therapies to help manage IBS symptoms.

Interactive elements are included all throughout the course, including videos, infographics, question-answer flip cards, sorting activities and interactive charts.

Course fees (Introductory offer)

USD $29.99

AUD $46 (incl GST)

Course completion is due 12 months from time of registration and payment.

Download Monash University's FODMAP App to find out details and how to apply for the course.

Understand your IBS today and learn how to manage your symptoms using a FODMAP diet.

The term FODMAPS is an acronym that stands for: **F**ermentable **O**ligosaccharides, **D**isaccharides, **M**onosaccharides and **P**olyols.

They're a group of poorly absorbed simple and complex sugars that are located in a variety of fruits and vegetables and additionally in milk and wheat.

After digestion of a meal, they pass through the stomach and small intestine unchanged and are either fermented with the aid of colonic bacteria releasing gas or expelled collectively with fluid. As a consequence in human beings with a sensitive gut of IBS, they are able to result in signs signs of bloating, stomach pain and diarrhoea.

NB: The bacterial populations of the colon require carbohydrates to remain healthful. Over-restriction can cause unfavorable changes to bowel and general fitness.

A few GP's are starting to advise that their sufferers move ahead with a FODMAP food plan, unfortunately they're unable to provide the help that's required whilst completing the weight loss plan programme. Preferably, your GP will refer you to a dietitian, according with regional guidance.

A dietitian has the knowledge to perform a full dietary and lifestyle evaluation and determine if the food regimen is appropriate and necessary.

We advocate that absolutely everyone following the food plan ought to do so under the supervision of a qualified FODMAP educated registered dietitian.

IBS is a common condition that influences the digestive system. It causes signs and symptoms like belly cramps, bloating, diarrhoea and constipation. These have a tendency to come and go over time, and may remain for days, weeks or months at a time. Tt's typically a lifelong problem. It may be very frustrating to live with and might have a large impact on your everyday lifestyles.

There is no remedy, however diet adjustments and medicines can frequently help manage the symptoms. The precise cause is unknown – it's been linked to things like food passing through your gut too fast or too slowly, oversensitive nerves on your gut, stress, and a family history of IBS.

The main common IBS signs and symptoms are:

- Stomach ache or cramps - Typically worse after eating and better after doing a poo
- Bloating - Your tummy may additionally feel uncomfortably full and swollen
- Diarrhoea - You could have watery poo and every so often need to poo unexpectedly
- Constipation - You may strain whilst pooing and feel like you cannot empty your bowels completely

There may be days when your signs and symptoms are better and days when they may be worse (flare-ups). they may be brought on by way of food or drink.

Norwood College raises $1900

As a proactive student at Norwood Secondary College in Ringwood North, Ashleigh Clifford decided to do a Social Studies project on Scleroderma.

Her linkage to the Pennicott family inspired her to not only do a school project, but an awareness event that included a hundred students and a talk from Scleroderma Victoria President Amanda Lawrie-Jones, Harrison and Miller Pennicott and Dyson Heppell as our Sunflower Hero and Scleroderma Ambassador.

It was a fun event which included a sausage sizzle, merchandise sales and lots of questions from curious students creating community awareness of Scleroderma.

The day raised $1900 for Scleroderma Victoria and promoted how the students could become Sunflower Heroes to continue the promotion of Scleroderma more broadly.

Some of the student at Norwood Secondary College with Dyson Heppell (centre) and young Harrison Pennicott.

Fashion, Fun, Friendship

More Than Skin Deep Parade highlights

The More Than Skin Deep Fashion Parade and High Tea was another successful day. This year the fashion was provided by eight different designers of men's and women's fashion.

The event was hosted by Dr Hannah MacDougall who is an elite Para athlete, dual Paralympian and Bronze Medallist, Inclusion Advocate, and has completed a PhD in Well-Being.

Hannah was discerning and generous in her understanding of Scleroderma and she also introduced the new video from Scleroderma Victoria showing insights from the medical profession regarding Scleroderma.

Firstly, our President, Amanda Lawrie Jones, interviewed Ann-Maree Heppell as one of our Sunflower Heroes. As always, the story of a family member of one who has supported someone with Scleroderma is a fascinating and insightful experience.

The female clothing designers were outstanding, firstly *Mazi,* which is a boutique Australian fashion label with feminine, romantic and vintage inspired clothing and accessories designed and made in Fitzroy, just around the corner from St. Vincent's Hospital.

Next was *Orocéo Castro* who are a Melbourne-based clothing brand founded by siblings, Paolo and Ginny Castro. Having hailed from the Philippines and calling Melbourne 'home', the brand has an aesthetic that can be described as a mixture of feminine, modern preppy, uptown chic and polished.

We moved on with *Nevada Duffy* who combines her ongoing interest in utility wear with her obsession for construction and the bespoke. She creates modern minimalism infused with structured silhouettes that evoke a quiet glamour.

Iva Pfeiffer Creations is a demi-couture designer label, focusing on customised, special event women's wear, based in Melbourne. Iva had a hands-on approach on the day assisting with choosing the models for Iva's original designs which have been called "wearable art".

Kwacha Luka is an African-Australian fashion designer who designs and makes custom made women and men's Special occasion, Costumes and Evening Wear. All products are made in Melbourne using a wide range of fabrics from African wax, lace to silk, using techniques such as painting, dying and fabric manipulation.

Along the way the women's fashion was accessorised by *Lady of Leisure Millinery* widely renowned for setting the new trend and celebrities and fashion stylists showcase her creations year after year. *The Lady of Leisure Millinery* designs were glamorous, elegant and sophisticated cool.

The mens fashion from *Mr. Robinson*, provided the latest suits and accessories with a range of formal wear that was modern, stylish and sophisticated. These were accompanied by the *Jimmy Fox* brand, the flamboyant and playful, yet remaining stylish and sophisticated.

Makeup artist, Sarah McMaster, applies the finishing touches to one of our models, Dr Mandy Nikpour.

This year our models were supported by Makeup Artist Sarah McMaster who is our Secretary, Jennene's daughter!

Again, this year Dr. Mandy Nikpour graced the runway in her usual style and class.

As well we had Lucia Hou who has consistently supported SV and is also Woman Of The Year 2018 and Guest Queen Cast of Channel 10 Documentary Series 'Behind The Sash'.

Also, a repeat performer was Fur Wale, International Speaker, Author, Mentor Entrepreneur and Editorial Model.

We were extremely lucky to have Minnie Dhillon, Ms South Asia Australia and Ms Australasia Globe 2019 don the catwalk for us this year as well as Poet Anthony, a professional model from *Brazen Models.* Along with the professionals we had Jen Ziegner who on her return from travelling without one pair of heels had her modelling debut and although nervous, she smashed it.

The men's models were Jamin Heppell, who also had his modelling debut on his return to Australia, with Clem Baade, another repeat supporter and Nicholas Inglese, the youth representative and son of event organiser, Louise Inglese.

The event itself was kicked off with the beautiful melodies from Elisha while the champagne was poured. Guests were ushered to their tables to enjoy the wonderful food from *Frankston International Catering* while enjoying the floral displays from *Secret Blossom.*

Again, this year we were supported by many individuals and companies for our 'Lucky Bag' Raffle with 30 prizes up for grabs. Our live Auction, by Paul Richards from *Bekdon Richards Real Estate,* was lively and profitable.

As always, thank you to the guests that attended another successful event full of fun, laughter and fashion. Raising awareness and funds for Scleroderma has been the aim, and, with our third year of this event, we have certainly done that!

We would like to thank our major sponsors, City of Yarra, Wilson Security, GB Galvanizing Service and the Strintzos Group.

Also all our sponsors who donated to our auction and raffle:

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Beware – the poison pill paracetamol

Most of us take paracetamol every now and again to reduce pain or fever. As far as medications go, it's one we're unlikely to associate with harm. But in a study published in the Medical Journal of Australia, my colleagues and I reveal a concerning increase in paracetamol poisonings, and resulting liver damage, in Australia over the last decade. In fact, paracetamol is actually the number one pharmaceutical Australian poisons centres receive calls about.

Paracetamol is safe if used appropriately, at a maximum of four grams per day in adults (equivalent to eight 500mg tablets, or six 665mg modified release tablets). However, when this dose is exceeded, there is a potential for harm. And the bigger the dose, the greater the risk.

It's time to consider restrictions, including reducing pack sizes and changing the way paracetamol is sold.

In our study we analysed data from national hospital admissions, poisons centre calls, and coroners' records to examine poisonings, liver injuries, and deaths.

The annual number of cases of paracetamol poisoning increased by 44 per cent from 2007-2008 to 2016-2017.

In that time, we recorded more than 95,000 paracetamol-related hospitalisations.

Liver injury from paracetamol has doubled over the same period. More than 200 people died from paracetamol poisoning in Australia in the 10-year period.

Paracetamol itself is not toxic, but in large amounts it overwhelms the body's ability to process it safely. This can lead to build up of a toxic metabolite (or break-down product), which binds to liver cells, causing these cells to die.

The quantity that constitutes a toxic dose depends on circumstances including the time period in which the paracetamol is taken, and the person's weight. But any adult ingesting more than four grams in a day could be at risk.

In severe cases, liver failure means the person will need a liver transplant, or they won't survive. Paracetamol is the leading cause of acute liver failure in the Western world.

There is an antidote to paracetamol toxicity, called N-acetylcysteine (NAC), which is given as an intravenous infusion in hospital. Importantly, NAC works best when given early: it should be started before any symptoms appear. Symptoms of paracetamol poisoning – nausea, vomiting and abdominal pain – indicate damage has already started to occur. Patients who take very large overdoses, and overdoses with modified release paracetamol, are more likely to sustain liver failure despite treatment with the antidote.

Modified release paracetamol comes in a higher strength, designed to be released over a longer period, which can be confusing and result in overdose.

Overdoses can be either accidental or intentional, and our figures include both.

Paracetamol is not a drug people become addicted to, or dependent on, in the same way people do with opioids or other drugs.

Intentional poisonings occur when people knowingly take too much paracetamol as a form of self-harm. In our research, about three-quarters of cases were intentional.

People might accidentally overdose because they are in pain, and believe because paracetamol is so widely available, it must be safe. They take more than the recommended dose, or take multiple different paracetamol-containing products together, resulting in harm. Poisons centres also receive calls about children having too much paracetamol, usually due to dosing errors or a child finding and ingesting the medicine.

It's important to be aware of the many brands of paracetamol-containing products, including cold and flu products, to avoid doubling up. People should also read the pack and ensure they follow the dosing instructions.

Parents should consider the following to avoid overdosing in children:

- paracetamol should be stored out of reach (for example, don't leave it on the bench or change table after use)
- paracetamol can be dosed every four to six hours, but must not exceed four doses in a 24 hour period
- keep track of doses given and when by writing them down
- read the label carefully and ensure you understand how to use the syringe/dosing device correctly.

Paracetamol poisoning and resultant liver injury is preventable, and some simple public health measures could have a significant impact.

In Australia, paracetamol can be purchased outside of pharmacies (for example, in supermarkets) in packs of 20 tablets. In pharmacies, packs of 100 can be purchased without needing to speak to a pharmacist.

In both cases, there are no legal restrictions on the number of packs one person can purchase. This is out of step with many other countries, especially the UK and Europe.

The UK restricted packs to 32 tablets in pharmacies and 16 tablets outside of pharmacies in 1998, as a response to increasing deaths from paracetamol. This resulted in a long-term reduction in paracetamol poisonings, liver injury, and deaths. Many European counties don't allow non-pharmacy sales of paracetamol, and have small packs in pharmacies. Denmark has gone one step further, restricting paracetamol sales to those aged 18 and over.

In our study, modified release paracetamol overdoses increased by 38 per cent each year and were disproportionately involved in deaths. Modified release paracetamol has been completely banned in Europe. This is due to documented harms, including increased risk of liver failure and death. The Therapeutic Goods Administration recently announced modified release paracetamol would become Schedule 3 in 2020, meaning it will be behind the pharmacist's counter.

This restriction is a step in the right direction but ignores the fact regular paracetamol can be purchased in large quantities without consultation with a health-care professional.

Due to its widespread use, paracetamol is likely to remain a common source of poisoning. Our study shows it's increasingly important we take measures to reduce harm from these events.

Restricting pack sizes and restricting availability of modified release paracetamol are crucial first steps. We also need increased public awareness of how to use paracetamol safely.

Chronic inflammation removes motivation

by Dr Liji Thomas MD

Why do we feel listless when we are recovering from an illness? The answer is, apparently, that low-grade chronic inflammation interferes with the dopaminergic signalling system in the brain that motivates us to do things. This was reported in a new paper published in the journal *Trends in Cognitive Sciences.*

The research carried out at Emory University explains the links between the reduced release of dopamine in the brain, the motivation to do things, and the presence of an inflammatory reaction in the body. It also presents the possibility that this is part of the body's effort to optimize its energy expenditure during such inflammatory episodes, citing evidence gathered during their study.

This could account for the reason Scleroderma patients some days have trouble motivating themselves.

The authors also published an experimental framework based on computational tools, devised to test the theory.

The underlying hypothesis is that the body needs more energy to heal a wound or overcome an infection, for instance, both of which are associated with low-grade inflammation. To ensure that energy is available, the brain uses an adaptive technique to reduce the natural drive to perform other tasks which could potentially drain away the energy needed for healing.

This is essentially a recalibration of the specialised reward neurons in the motivation centre of the brain, so that ordinary tasks no longer feel like they're worth doing.

According to the new study, the mechanism of this recalibration is immune-mediated disruption of the dopamine pathway, reducing dopamine release.

The computational technique published by the scientists is designed to allow experimental measurements of the extent to which low-grade inflammation affects the amount of energy available, and the decision to do something based on the effort needed. This could allow us to better understand why and how chronic inflammatory states cause a lack of motivation in other disease conditions as well, including schizophrenia and depression.

Andrew Miller, co-author of the study, says, "If our theory is correct, then it could have a tremendous impact on treating cases of depression and other behavioural disorders that may be driven by inflammation. It would open up opportunities for the development of therapies that target energy utilization by immune cells, which would be something completely new in our field."

It is already known that immune cells release cellular signalling molecules called cytokines, which affect the functioning of the dopamine-releasing neurons in the area of the brain called the mesolimbic system. This area enhances our willingness to work hard for the sake of a reward.

Recently, it was discovered that immune cells also enjoy a unique capability to shift between various metabolic states, unlike other cells. This could affect cytokine release patterns in such a way as to signal the brain to conserve available energy for the use of the immune system.

These facts were the foundation of the new hypothesis, which explains it in terms of evolutionary adaptation. In the hypothetical early environment, the immune system, faced with abundant microbial and predatory challenges, needed tremendous amounts of energy. It therefore had its own mechanism to signal other body systems, via the mesolimbic dopamine system, to control the use of energy resources during periods when the organism was undergoing severe or sudden stress.

Modern life is relatively soft and less challenging. With less physical activity, low-grade inflammation is chiefly due to factors such as obesity, chronic stress, metabolic syndrome, aging and other lifestyle illnesses. This could mistakenly cause the mesolimbic dopamine neurons to produce less dopamine. Lower dopamine levels in turn decrease the motivation for work, by reducing the perception of reward while increasing the perception of effort involved. This ultimately conserves energy for use by the immune system.

Previous studies by Miller as well as other scientists have shown that a high level of immune functioning in association with low levels of dopamine and reduced motivation characterizes some cases of schizophrenia, depression and certain other mental health conditions.

The scientists do not think these disorders are caused by the low-grade inflammation, but that some people who have these illnesses are hypersensitive to immune cytokines. This could in turn cause them to lose motivation for daily living.

The scientists are currently performing a clinical trial on people with depression, to test the theory using the computational framework.

Travelling overseas with Scleroderma

by Margery Cairns

When I developed scleroderma about eight years ago which included gastrointestinal tract problems requiring a nightly infusion of Total Parenteral Nutrition (TPN}, I thought my days of travelling over-seas had ended.

Having recently retired, we had planned to do as much travelling as possible in the following years.

We have just proved that with careful preparation and the help of a marvellous medical team at St. Vincent's, it is possible.

I am currently on TPN every second night and my symptoms are much less severe than when I first became ill. We have travelled to many places in Australia and Baxters have successfully arranged to ship the TPN to several different addresses.

Travelling to another country presented a number of problems: How could 1.5 litre bags of TPN which require refrigeration be carried or obtained, would it be possible to take all the necessary equipment and medications with us, could I obtain insurance, would the Body guard 323 pump work with a different voltage, what if the Hickman's catheter needed replacing - the list of practical problems seemed endless.

On the positive side we planned to visit Canada, our home for many years and knew that the health system was excellent. Also, for much of the time we would be staying with friends. So, with the help of John Gough and Dr Sally Bell at the nutrition clinic we started to plan.

Our proposed trip for five weeks included a week in Vancouver, touring the Rocky Mountains for a week, three days in Calgary, a week in Toronto and finally visiting our former hometown Deep River where we would celebrate our 50th wedding anniversary with several old friends, including my bridesmaid.

We organised the Rocky Mountains tour with Fresh Tracks Canada and while they were very helpful, we could not plan dates for the tour or purchase air fares until all the medical details were sorted out.

A positive start was finding that I would be covered by insurance and the company, Baxters, exists in both Australia and Canada.

Margery and Jim on the Athabasca Glacier in the Rocky Mountains

*TPN - Parenteral nutrition, often called **total parenteral nutrition,** is the medical term for infusing a specialised form of food through a vein (intravenously)*

John Gough (Scleroderma Nurse at St Vincent's) spent many hours liaising with the Canadian branch and eventually it was arranged that bags of TPN would be delivered at our friend's homes in Vancouver and Toronto prior to our arrival.

Also, the TPN was a type that did not need refrigerating, the bags were only one litre and the pump would work on a different voltage.

I trialled using the one litre bags and with the help of Manny at the St. Vincent's pharmacy, a tablet was prescribed that would supply the missing vitamins.

We made careful lists of all the medications and equipment we needed to take including a few spares. Dr Marno Ryan wrote us a covering letter and we had a list of all the medical items.

Finally, we were ready to go!

At Melbourne airport the pump and list of items were of most interest. The three Canadian airports Vancouver, Calgary and Toronto have computerised screens with details to fill in and very helpful airport employees to assist if necessary.

On our return we found that Melbourne is developing similar systems and we did not have to line up and be questioned by custom employees as in the old days.

Everything went according to plan, we coped with "hooking up" in different locations, an elasticised chord with hooks either end (bungy strap?) was useful for hanging the bag. I used swabs for cleaning and a kidney dish was handy.

For most of the time I was really well and a few episodes of feeling unwell were about the same frequency as usual, and more likely the result of overindulgent eating.

What made it all possible was the excellent medical team working on my behalf and the co-operation of Baxters both here and in Canada.

We had an amazing holiday, the tour through the Rockies was sensational and all our friends made sure we had a great time.

The non-refrigerated one litre TPN bags were much easier to hook up and store than the standard larger bags that require refrigeration.

When I returned my blood test results were all normal showing that the different type of TPN had no detrimental effects.

A big thank you to John Gough, Marno Ryan, Sally Bell, Clara Newsome, Man Lee and Baxters for making it happen.

Year-end joy for Support Groups

December saw our Support Groups across Victoria get together to celebrate Christmas and the coming holiday season.

Our Support Groups have been meeting throughout the year for members wishing to get together for a chat over lunch or coffee to discuss a wide range of subjects not always related to Scleroderma.

Scleroderma Victoria's Support Groups are coordinated by Judy Browning who also runs the Bendigo Support Group.

We have groups in Mornington, the Western Suburbs, Bendigo, North Eastern Suburbs, Ballarat, Geelong, Inner South Eastern, Gippsland and Albury-Wodonga. A full list is on Page 16 or you can contact Judy on 0419 885 894.

If you wish to start a group also contact Judy. The groups are an important part of our Scleroderma fellowship.

Bendigo Sclero! Bring on 2020

Christmas wasn't the same this year, as we gathered together for our break-up and to remember two of our members tragically killed in a car accident.

Lyn and Bruce Anderson, who were keen campers, will be sadly missed by the Bendigo Support Group. They are pictured right.

Still, we managed to break out the tinsel, dust off the holly and got merry at our Christmas gathering at the Marong Hotel, the regular watering hole of Sclero Bendigo, just as Lyn and Bruce would have liked us to.

In October Bendigo Scleroderma got together to remember and honour Lyn and Bruce. We sent our deepest condolences to Lyn's mother Thelma (a frequent lunch partner also) and their large family and wide circle of friends.

The cheer, friendship and strength brought by Lyn and Bruce will be remembered for a long time. Vale Lyn and Bruce.

We are all looking forward to 2020, it's much easier to write and remember!

Come on down or up as the case may be and call Judy Browning on 0419 885 894 if you would like to join us. It's on again on February 26, 2020, at the Marong Hotel, of course.

- ***Judy Browning***

WESTIES

Research groups to battle Scleroderma

by MARY CHAPMAN in Scleroderma News

A new collaboration between Servier Pharmaceuticals of the United States and University College London (UCL) seeks to speed the discovery of new therapies for immune-inflammatory disorders such as Scleroderma.

The initial two-year agreement calls for Servier to share scientific knowledge with UCL researchers who are investigating how scleroderma develops, as well as modified pathways in lupus.

The premise is that a better understanding of disease processes will lead to new therapies.

"We know how the body's immune system switches off some functions after it's responded to bouts of infection or experienced an injury," Derek Gilroy, chair of experimental inflammation and pharmacology at UCL Medical School, said in a press release. "We think that these internal checkpoints are altered in people who have chronic inflammatory diseases."

Also known as systemic sclerosis, scleroderma is a chronic disease that affects connective tissue. It is characterized by thick and hardened skin caused by excessive production of collagen, the chief component of scar tissue. For this project, scientists want to uncover scleroderma's molecular and cellular makeup.

"Scleroderma is a disease that leads to scarring and fibrosis in many organs, with limited treatments available," said Christopher Denton, PhD, a professor of experimental rheumatology at UCL Medical School. "This collaboration will help define the potential of new treatment approaches that could have long-term impact in scleroderma, but also in many other diseases where scarring and blood vessel damage occur."

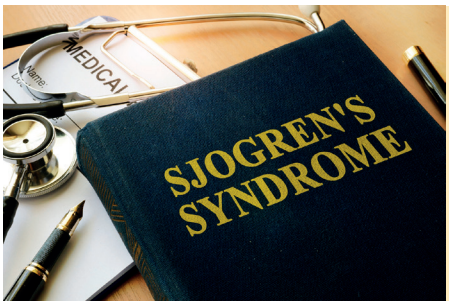
Claude Bertrand, executive vice president of research and development at France-based Servier, called collaboration with academia a key part of the company's treatment discovery and development strategy. "The UCL team we're working with have considerable expertise in both lupus and systemic sclerosis, and they're based at one of the top institutions for medical and health research globally," he said. UCL's Division of Medicine has been successful in immune-inflammatory diseases, pioneering the use of rituximab to treat rheumatoid arthritis, said Robert Kleta, the division's director. Rituximab, sold under the brand name Rituxan in the U.S. and MabThera in Europe, has been used off-label in people with scleroderma.

"We're looking forward to creating synergies between Servier and UCL scientific expertise, with the aim of a successful and fast translation into therapeutic solutions for the benefit of patients suffering from lupus and systemic sclerosis," said Philippe Moingeon, PhD, head of the Servier Center for Therapeutic Innovation in Immuno-Inflammatory Diseases.

Celia Caulcott, UCL vice-provost of Enterprise, said she believes the partnership will be a model for future collaborations between academia and industry.

"The major health challenges of the 21st century involve conditions with complex, multifaceted pathology, and making progress will require collaboration between the best research minds in universities and our innovative partners in industry," she said. "The immune-inflammatory diseases are an excellent case in point."

Sjogren's – relieving symptoms



Sjogren's Syndrome is a primary autoimmune disease and also a secondary disease for many people with Scleroderma, Lupus, Rheumatoid Arthritis etc.
As a secondary disease it's impact can be a mild irritation or severe.

In Sjögren's syndrome, immune cells infiltrate and destroy the mucus-producing glands of the body.

Sjögren's syndrome can occur by itself (known as Primary Sjögren's syndrome), or together with other autoimmune diseases like Scleroderma, lupus or rheumatoid arthritis. This is known as Secondary Sjögren's syndrome.

Although the specific cause of Sjögren's syndrome is somewhat of a mystery, there appears to be a genetic influence. It tends to occur more commonly in families that have other autoimmune diseases.

It is also thought several factors can trigger the disease – including viral infections, hormones and stress.

There's currently no cure for Sjögren's syndrome, but proper treatment should provide comfort and relief of symptoms.

Risks

Ninety per cent of people with Sjögren's syndrome are women. On average they are diagnosed between the ages of 40 and 50.

As most patients are women, the antibodies in their blood can be passed to an unborn child via the placenta.

This can lead to the development of neonatal heart block and can stop the baby's heart from working properly. Approximately 1 in 50 pregnant mothers with Sjögren's syndrome have a child with neonatal heart block.

The incidence of neonatal heart block increases to 1 in 5 for subsequent pregnancies in mothers who previously had a child with neonatal heart block.

Some patients with Sjögren's have enlarged lymph glands and spleens; this can lead to an increased risk of developing cancer, specifically lymphomas.

Like many autoimmune diseases, people with Sjögren's syndrome are at increased risk of developing cardiovascular disease, potentially due to ongoing inflammation. Other serious but less common complications affect kidney, lung and liver function.

Symptoms

The symptoms vary greatly between individuals and may include:

- Dry eyes and few or no tears: the most frequent complaint is the sensation of a foreign body in the eye. Redness, burning, light sensitivity, eye fatigue and itching may also be present.
- Dry mouth: including difficulty chewing, swallowing food or speaking. Ulceration of the tongue and cheek membranes, a burning feeling on the tongue, altered taste sensation and the need to frequently drink fluids are common.
- Bacterial overgrowth in the mouth: saliva is important for its antibacterial function, so without adequate saliva, dental decay, periodontal disease and oral yeast infections may develop.
- Dry ear and nose: this may result in Eustachian problems of the middle ear or crusts, bleeds and a reduced sense of smell.
- Fatigue and/or depression.
- Vaginal dryness.
- Swelling and pain in the joints.
- Numbness and pins and needles.
- Muscle weakness.
- Dizziness.
- Nausea, vomiting, early satiety and abdominal bloating.
- Kidney stones.

Diagnosis

Blood tests can detect certain antibodies in Sjögren's syndrome, although this isn't a thorough diagnosis.

A specialist eye examination, and occasionally kidney and lung function tests are needed to complete the diagnosis.

Eye tests include Schirmer's test: a paper strip that measure the production of tears. Normally people wet the paper very quickly, but in Sjögren's syndrome, the paper may still be dry.

An ophthalmologist may perform a slit lamp examination, where a special lamp scans the surface of the eye and identifies abnormalities of secretion or the cornea.

A dye that identifies mucous material may also be put into the eye to reveal a characteristic pattern for Sjögren's syndrome. A lip biopsy may be taken under local anaesthesia to sample salivary glands and reveal the degree of damage.

There is currently no cure for Sjögren's syndrome, so treatment aims to relieve the symptoms.

A variety of artificial tear preparations can be used to treat dry eyes.

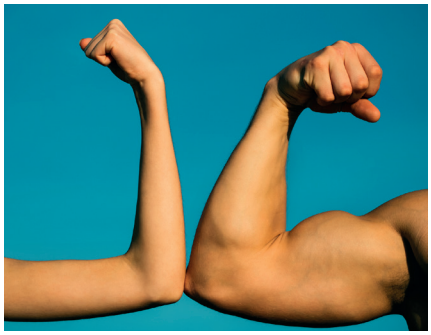
There are some oral lubricants for treating symptoms of a dry mouth, but none are entirely satisfactory. Chewing sugarless gum may be helpful.

Good dental hygiene and frequent visits to the dentist are essential.

Moisturisers can help people with dry skin and lubricating creams may help dryness of the vagina.

Oral medications, including non-steroidal anti-inflammatory drugs, can be used to treat swollen and painful joints.

Sarcopenia may affect up to 55% of patients with SSc



Loss of muscle mass and strength — known as sarcopenia — may affect up to 55% of patients with systemic sclerosis (SSc), a study suggests.

Moreover, sarcopenia was found to be associated with several clinical and nutritional parameters of disease severity. The study, "Sarcopenia in systemic sclerosis: the impact of nutritional, clinical, and laboratory features" was published in the journal *Rheumatology International.*

People with rheumatic diseases — including rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, systemic lupus erythematosus, and fibromyalgia — are more prone to develop sarcopenia, the loss of muscle mass and strength that may progress to disability.

SSc is a chronic autoimmune rheumatic disease, and two recent studies have estimated a prevalence of 20.7 per cent to 22.5 per cent of sarcopenia among SSc patients.

In one of the studies, sarcopenia was associated with duration and severity of the disease, namely lung and skin involvement.

Now, a team led by researchers at the University of Siena, Italy, evaluated the presence of sarcopenia in 62 SSc patients — 50 with limited cutaneous SSc and 12 with diffuse cutaneous SSc — using two common tools to assess muscle wasting, the hand grip strength (HGS) and the Relative Skeletal Mass Index (RSMI) test.

The researchers also evaluated clinical and lab parameters, as well as patients' nutritional status, including lean body mass (LBM) and vitamin D levels.

According to RSMI, sarcopenia is defined as a score below 7.26 kilograms per square meter in men, and below 5.50 in women. According to these values, researchers found that 26 SSc patients (42 per cent) in the cohort analysed were positive for sarcopenia.

Age, as well as malnutrition and LBM, influenced the prevalence of sarcopenia. Longer disease duration, and higher scores in the modified Rodnan skin score (mRSS), as well as increased inflammation (as measured by the erythrocyte sedimentation rate) were also associated with sarcopenia.

"mRSS was on an average four times higher in sarcopenic cohort than in non-sarcopenic one," researchers stated.

Researchers also found that the presence of antinuclear antibodies — those reacting against proteins inside cells — and a reduction in the lungs' diffusing capacity for carbon monoxide (DLCO) — a test of the lungs' capacity to transfer oxygen from the air sacs into the blood — also correlated with sarcopenia.

Quality of life, measured by the Short Form Health Survey (SF-36), was significantly lower in sarcopenic SSc patients.

Using the HGS, whose scores below 30 identify sarcopenia in men and below 20 in women, the prevalence of sarcopenia in this SSc population was 54.8% (34 patients affected).

The team also emphasised that "all patients with [diffuse cutaneous] SSc resulted [as] sarcopenic according to the HGS index."

Overall, "by using both RSMI and HGS to assess sarcopenia in SSc, the results of this study demonstrated that this condition correlates with different nutritional, clinical, and biochemical parameters associated with the worsening of the disease," the team concluded.

Donations to Scleroderma Victoria

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Meet your Member

Louise Inglese

Louise joined the committee in 2016 to assist with fundraising. Having a background in sales it seemed an obvious opportunity to serve a cause close to her heart by raising funds and awareness for Scleroderma Victoria.

Louise comes from a family of philanthropy and fundraising who have used their resources to make a difference in the lives of others.

Louise's diagnosis of scleroderma came through her gastroenterologist due to other auto-immune conditions that she has.

What made you support Scleroderma Victoria and what were the reasons you became a paid member?

After my diagnosis the first thing I did was 'Google' scleroderma. There is so much information from so many sources that were very daunting and depressing.

Knowing that Scleroderma Victoria offers members support and access to their services was a relief to me.

By joining Scleroderma Victoria, I have benefited from being part of a larger scleroderma community especially with our support groups, conferences and newsletters. As scleroderma is a rare condition we need as many members to help voice issues with the medical profession and our government.

Why did you become a Committee Member?

After holding my first fundraiser, which was a huge success, I knew that being on the committee could mean that I could make a real difference.

Raising awareness and funds for Scleroderma Victoria is the ultimate use of my time and effort.

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

For the past year I have been the Leader of the Mornington Peninsula/ Westernport Support Group.

This has been a fantastic role where I have the privilege of supporting our members in my area. This is vital link for members and carers to feel a sense of self-respect, understanding and belonging by being part of a circle of a caring community, with knowledge that we are not isolated.

Through our Group I have met some of the most positive, resilient, inspiring people and feel honoured to have them in my life.

What would you like to see Scleroderma Victoria achieve in 2020?

As 2019 is the 40th anniversary of Scleroderma Victoria, we have launched Scleroderma Victoria's Target 400 campaign to increase the membership base.

The more members that we, as a committee represent, the more influence we can have over policy and funding.

I hope that we can achieve the target and more.

Tell us about your other interests and what drives you?

I am a mother of three children and my favourite place is in the garden with my dogs, cats and chickens or hanging out with my family.

I run an export business which my husband and I are very proud of and I enjoy the professional challenges of a global business.

SCLERODERMA VICTORIA DIRECTORY

Incorporation No. A001798A
ABN 45 674 166 348
All correspondence to: Scleroderma Victoria,
PO Box 57, Melton, Victoria 3337
Telephone: (03) 9231 3651 (Please leave a message)
Website: www.sclerodermavictoria.com.au
Email: enq@sclerodermavictoria.com.au

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
Bridget Naughton
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)

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
Heather Hollaway - 5792 2365