

ASIG celebrates 10 years of research

There was a total of 150 registered attendees at the recent Australian Scleroderma Interest Group's (ASIG) 10th Birthday celebrations at St Vincent's Hospital in Melbourne.

They were welcomed by Associate Professor Dr Susannah Proudman who gave an overview of the history of ASIG.

A brief overall description of scleroderma was presented, outlining all the various conditions which this disease may present.

This was followed by an update on the progress of research into the treatment of various associated scleroderma symptoms by Associate Professor Dr Mandy Nikpour.

After a short question time there was a presentation of cheques totalling \$50,000 from Scleroderma Victoria to ASIG for Research.

The money will go towards specific research projects.

This included \$23,000 from the Estate of the late Graham Copsey to Scleroderma Victoria which was subsequently donated to ASIG. Graham's family members attended the presentation. Graham was a former President of Scleroderma Victoria.



A merchandise stall at the symposium raised nearly \$300 for Scleroderma Victoria. The picture at left shows members Annette and Margaret manning the stall at Melbourne's St Vincent's Hospital.

ASIG AWARD

ASIG received a well-deserved birthday present at the Australian Rheumatology Association (ARA) annual conference.

ASIG was awarded the ARA President's Prize for Collaborative Research.

Associate Professor Mandy Nikpour said "This prestigious award is a fitting acknowledgement of the important work of ASIG and would not have been possible without your support and collaboration. "I look forward to many years of fruitful collaboration yet to come, and to seeing ASIG go from strength to strength with your support."

** See Pages 3 and 12 for full coverage of presentations.*



Scleroderma Victoria President Amanda Lawrie-Jones presents a cheque for \$25,000 to go towards Scleroderma research to ASIG's Dr Jo Sahhar at the recent 10th birthday symposium for members. Looking on is Associate Professor Susanna Proudman.

FROM THE PRESIDENT Amanda Lawrie-Jones

Time flies when you're having fun

Where does the time go! The year has kicked off with a bang, and the excitement of what we have in store for our members and community of people with scleroderma looks to be a good one.

We ended 2017 with the fantastic Sounds of Summer event in Leongatha on December 29 and raised just over \$2500. Sounds of summer is a family friendly food, wine and music festival.

It showcased some great Aussie talent and local artists, bringing together local business as well as local community groups.

We were lucky enough to be the 'Charity of Choice' and want to thank the festival for their generosity and our Committee Members Bruce Mannion and Louise Inglese for flying the flag for us on the day.

Our Sunflower Heroes have been busy in raising funds and creating awareness for us. Michael Papworth got into the full beard of things all for a great cause. As a fun way to create awareness and raise funds for Scleroderma Victoria, he took on a challenge to grow his beard for 12 months, followed by a 'shave-off'. An amazing effort in raising more than \$5000.

Another Sunflower Hero Elisha Whyley and her young son organised a casual day for gold coin donation at Montmorency South Primary School. They raised \$543.

A huge thank you to both for being active Sunflower Heroes and we appreciate your efforts.

We value our Sunflower Heroes and welcome you to invite your family, friends and colleagues to get into the spirit of fun and fabulous fundraising ideas!

Our Scleroderma Victoria Ambassador, Dyson Heppell, has been busy too making a little boy's dream come true. The story of Mr H is on page 5. Dyson has also committed to our World Scleroderma Day lunch at The Grand Hotel on Saturday, June 30.

As always, our Committee have been hard at work preparing for the upcoming year, and here is a snapshot of the great events ahead in 2018:

World Scleroderma Day Lunch - June 30

More than Skin Deep Fashion Parade - October 14

Monash Fundraising Stall - June 25

This year, we are also looking to focus more on Support Groups. The benefits of connecting with others and sharing your experiences can provide greater understanding and support for all.

I had the pleasure of attending a Bendigo Support Group lunch a month back which was most enjoyable. I was made very welcome and thoroughly enjoyed myself.



Our President Amanda (left) with Scleroderma Victoria Support Group Co-ordinator, Judy Browning at the Bendigo Group lunch.

We welcome any new Support Group Leaders, so please let us know if you are willing and able to kick one off in your area. We are here to help.

Our new and reinvigorated long-term strategy is on its way, and it will provide us with a vision of our goals for the future. Keep an eye out on our website for further information.

We at Scleroderma Victoria all hope your 2018 has been great so far, and we look forward to seeing you at our events and having you involved in our progress for the future.



Keeping time with Uncle Jack

Uncle Jack Watches have teamed up with Dyson Heppell to create a unique 3-piece range of watches to help fight Scleroderma.

Every watch purchased will help fight Scleroderma.

Together with Dyson Heppell, they have designed a unisex range that is crisp, balanced and premium.

A limited number of watches are available & they're likely to sell out.

Get yourself onto the waiting list to treat yourself to a fresh watch & support an important cause!

<https://vip.unclejackwatches.com/dh-x-uj/>

ASIG celebrates a decade of scleroderma research

Celebrating ten years of research by the Australian Scleroderma Interest Group (ASIG): a summary of a Public Lecture discussing ASIG achievements and scleroderma research advances.

- by Mandana Nikpour and Susanna Proudman

To mark 10 years of scleroderma care and research by the Australian Scleroderma Interest Group (ASIG), a Public Lecture was presented to over 150 registered attendees at St. Vincent's Hospital Melbourne on Friday, May 4, 2018.

A/Prof Susanna Proudman, rheumatologist at Royal Adelaide Hospital and the University of Adelaide presented on the topic 'The Australian Scleroderma Interest Group (ASIG): how far have we come?', while A/Prof Mandy Nikpour of St. Vincent's Hospital Melbourne and the University of Melbourne presented on the topic 'Update on scleroderma research: what does the future hold?'

A/Prof Proudman began her lecture by giving an overview of scleroderma and its many possible organ manifestations, including skin thickening, finger and toe ulcers, heart-lung and gut involvement.

She spoke about the importance of working towards a treatment goal, which can in turn be achieved through accurate measurement of disease 'activity' as opposed to irreversible organ 'damage'.

A/Prof Proudman spoke of the work of ASIG in leading international collaborations to develop clinical tools to identify and measure disease activity and damage in scleroderma.

She also presented prize-winning research undertaken by ASIG fellow Dr Kathleen Morrisroe to quantify the 'burden' of scleroderma in terms of hospitalisations and visits to health practitioners including allied health professionals, and loss of employment and work productivity.

This work has highlighted areas, in particular hand, heart-lung and gut involvement, that contribute significantly to both hospital admissions and loss of ability to work. This project has highlighted the importance of further research in these specific areas to reduce disease impact and improve quality of life for people living with scleroderma.

A/Prof Nikpour then spoke in more detail about heart-lung involvement in scleroderma, in particular pulmonary arterial hypertension (PAH), a condition where the blood vessels in the lungs are narrowed, leading to reduced flow of blood through the lung, eventually placing strain on the heart, and interstitial lung disease (ILD), a condition of scarring ('fibrosis') in lung tissue resulting in reduced lung expansion and breathlessness.

A/Prof Nikpour discussed the importance of annual screening for PAH in everyone who has scleroderma, which both in Australia and other countries, has been shown to improve quality of life and survival by enabling early initiation of treatment.

She spoke about the limitations of echocardiography in PAH screening, as the specific expertise required to obtain accurate measurement is often only available in large centres and the pressure cannot always be measured.

Over the past 10 years, ASIG has developed a new algorithm for PAH screening that utilises a blood test named NT-proBNP together with lung function tests to identify patients at risk of having PAH who then require further investigation in a specialised centre.



Graham Copsey's daughters Jane, Sue and Sarah present their father's cheque to ASIG researchers (from left) Dr Susanna Proudman, Dr Wendy Stevens, Dr Jo Sahhar and Dr Mandy Nikpour.



Graham Copsey - left a generous donation to Scleroderma Victoria for Research - see page 12

Future ASIG research will focus on the implementation of this algorithm in routine clinical care, with a view to the future listing of this test on the Medicare Benefits Schedule. This would reduce the number of echocardiograms people need to have and make screening more widely available. The newly proposed ASIG PAH screening algorithm has the potential to save costs through performance of fewer echocardiograms and may improve access to PAH screening for people who live in regional and remote areas.

In addition to studies of PAH screening, ASIG researchers continue to perform projects to determine the best combination of treatments for scleroderma PAH. In particular they are undertaking a study looking at whether or not the addition of blood thinning medication to specific therapy for the PAH will improve the outcome for people with PAH.

This study is named the SPHINX SPHInX clinical trial and is still recruiting new participants. If you have PAH, you may wish to discuss with your doctor if you might be suitable for this study.

Whilst some degree of ILD is a common finding in scleroderma, affecting up to 60 per cent of people with scleroderma, for most

...Continued on page 12

Two new portable oxygen concentrators

The Brunswick United Lodge of the Freemasons have been generous supporters of Scleroderma Victoria for many years.

They've teamed up with the Freemasons Foundation of Victoria to provide sufficient funds for the purchase of a new portable oxygen concentrator (POC).

Our Secretary; Jennene Caton, wrote a convincing letter to the Freemasons, explaining what a POC is and how it can improve the quality of life for someone living with lung involvement due to Scleroderma.

This resulted in a very generous cheque, which was presented last year to our President; Amanda Lawrie-Jones, at our Conference and AGM by a representative of the Brunswick United Lodge; Mr Bob Hess.

The new machine has been purchased and has been helping one of our members since January 2018.

Jennene is pictured (right) handing over one of the new machines to Mr Ian Cronjaeger to be used by his wife.



Arthritis SA CEO Julie Black (left), Pauline Sim and SA Governor Hieu Van Le.

Governor honours Pauline

Pauline Sim has been presented with a 'certificate of Appreciation' by the Governor of South Australia, Hieu Van Le, for her work with the Lupus, Scleroderma, Sjogren's Group in Adelaide.

Pauline was delighted to be invited to attend a reception at Government House for the presentation for supporters and volunteers of the Arthritis Foundation of South Australia.

"The grounds, house, furniture and artworks were beautiful", said Pauline.

"The Governor and his wife were so gracious! Little did I know that I was to be awarded a 'Certificate of Appreciation'. I was utterly thrilled".

Pauline said she also wanted to thank Arthritis SA Chief Executive Officer, Julie Black, for the award.

Hieu Van Le AC is the 35th and current Governor of South Australia since 1 September 1, 2014. He served as the state's lieutenant-governor from 2007 to 2014.

Tips for Raynaud's

With winter fast approaching we've put together a list of six tips to help manage Raynaud's phenomenon flares based on information from the Sjogrens Syndrome Foundation.

Warm Water

When you come in from the cold, one of the quickest ways to bring your hands (and feet) back to their normal state is to run them under some lukewarm water or soak them in warm water until the color comes back.

Quit Smoking

Smoking restricts blood vessels (among many other things) so it will compound your Raynaud's phenomenon symptoms.

Moisturize

The change between hot and cold temperatures will wreak havoc on your skin and dry it out quite quickly. Invest in some quality hand cream and apply frequently throughout the day. A foot cream can be liberally applied to the feet first thing in the morning and before bed.

Increase Blood Circulation

When you start to feel the temperature dropping in your hands and feet, wriggle your fingers and toes, stamp your feet, or put your hands somewhere on your body to warm them up, like in your back pockets or under your armpits.

Bundle Up

Extra socks, warm boots, fleecy gloves, and heated hand warmers are good ways to stop the cold from penetrating and will help ward off Raynaud's flares. Ask other people to take things out of the freezer for you, or wear gloves when doing so.

Review Your Medication

Certain medications such as beta-blockers can make the symptoms of Raynaud's worse and there are medications that your doctor can prescribe to help ease the symptoms such as calcium channel blockers.



Mr H kicks to Dyson.

Mr H meets the Bombers

At the Royal Children's Hospital Good Friday Appeal, little Harrison said on National television that his favourite superheroes were the Bombers.

Well, thanks to Scleroderma Victoria and our Ambassador Dyson Heppell, not long after, little Harrison and his big brother Miller got the treat of their lifetime – meeting the Bombers and their captain Dyson.

Wow what a great experience. Not only did Harrison meet the Bombers, he got to kick the footy with Dyson, tour the locker rooms and even try a bit of boxing.

Harrison, or, as many of his friends and family know him, Mr H. is a bright, bubbly, five-year-old boy. He loves Lego, superheros, the Bombers and playing (mostly, happily) with his big brother, Miller.

Harrison suffers from a very rare autoimmune disease called Scleroderma, typically characterised by thickening or hardening of the skin.

Harrison is the youngest Australian ever diagnosed with Scleroderma, which affects around 6000 Australians. Not only does Harrison have this rare disease but the rarest form: Disabling Pansclerotic Morphea.

There is no cure.

While easily taken for granted, our skin is our largest organ and body's first line of defence. It protects us, regulates our body temperature, rids our body of toxins and prevents chemical and waste build-up.

When our skin is healthy, happy and comfortable, so are we.

Harrison's Mum Leesa Pennicott, says Scleroderma impacts how any healthy child Harrison's age would spend their days.

"Harrison can't cope playing in the sun for periods of time like his friends, his skin is tight and restrictive particularly across his face, hands and feet.

"He overheats quickly. Daily medication needed to manage his condition lowers his immune system. This means he gets infections or viruses easily, but with very few obvious symptoms.

"Despite this, Harrison is one of the happiest boys we know. He never complains about what he goes through daily, or throughout frequent hospital visits. Rather, he smiles each day and plays to the best of his ability.

"Our rheumatology department at the Royal Children's Hospital in Melbourne has shown Harrison nothing but tireless support, love and care.

"And to date – as a show of humble thanks – we've raised \$8500 for RCH through the 'Run for Fun' (2016) and 'Run For The Kids' (2017)."

Leesa says "I'm not about to stop there. "My (not so secret) mission for 2018 is to raise as much awareness about Scleroderma as possible, and a further \$10,000 to be shared between Melbourne's Royal Children's Hospital and Scleroderma Australia. "To achieve this, I'd like to ask for your help, and to join our family and friends who continue to walk this long road with us.

"Business sponsorship; individual or group fundraising; direct donations to our Go Fund Me page; joining 'Team Harrison' for the 2018 Run For The Kids.

Anything to reach our \$10,000 goal would be amazing. Follow Harrison's journey with regular updates from Leesa on Facebook.



Dyson with Mr H (right) and his brother Miller.



Mr H (left) meets Coach John Worsfold and Dyson.

Support Groups help each other

A Support Group follows the belief that individuals who have lived experience of life issues such as disability, mental health, and/or a life-changing event, can better relate to other individuals trying to deal with similar issues.

By listening empathetically, sharing their experiences and offering suggestions based on that experience, people with a lived experience are uniquely able to help others like themselves.

When people find affiliation with others they feel are like them, they feel a connection. This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to be with each other without the constraints of traditional relationships.

Sharing lived experiences provides multiple perspectives of the experience, thereby broadening understanding. The accumulated knowledge drawn from the lifelong learning journeys of many people becomes an invaluable source of insights and an unmatched source of support and inspiration for people dealing with life-changing events.

The Support Group approach promotes a wellness model. Assisting a person to find and develop their own personal resources empowers the individual with the belief that they can and do have control over their life.

A Support Group offers an additional approach which can be either complementary to clinical services or, in some cases (depending on the severity of the illness), stand-alone.

Program Objectives

In line with Scleroderma Victoria's vision, we aim to support our members and their families with Scleroderma and ensure they are provided with a positive and transparent attitude with the promotion of Support Group activities.

A Support Group program provides a vital link for individuals and carers to ensure there is a renewed sense of self-respect, understanding and belonging through being part of a circle of a caring community, with knowledge that they are NOT isolated.

A Support Group Program aims to:

- Increase self-esteem
- Enable better decision-making skills
- Improve social functioning
- Lower rates of isolation, larger social networks, increased support seeking
- Greater strength gained from realising that they are an important part of both a group
- and the community and take that strength out into the community
- Provides opportunities to make authentic connections that increase well-being socially, mentally, physically and spiritually
- A means to alleviate stress and improve well-being for carers
- Gain and share knowledge of skills, treatment pathways and tools that have proven useful



Why a Support Group?

Why put time and effort into running a support group? I personally get a lot of satisfaction from seeing the different members of the group meet others who understand what they are going through.

There's something special about not having to explain what scleroderma is all about, let alone how to pronounce the name.

Seeing the members share together their journey with scleroderma and learn from each other's experiences is very rewarding.

When the group meets up I try and ensure everyone gets a chance to share if they want.

Sharing together how we are travelling and any issues we are currently facing can benefit us all when it is done in a safe environment. I also feel it's important that we don't just talk medical all the time but explore other topics together as we get to know each other.

It's great when we can have a laugh together too.

I like to let the members know of any Scleroderma Victoria events that are coming up and encourage them to attend.

A set of guidelines for running a support group have been put together by the Scleroderma Victoria Committee and are available for anyone wishing to start a group in their area. The main objective of the support group program is to provide a vital link for individuals and carers to ensure there is a renewed sense of self-respect, understanding and belonging through being part of a circle of a caring community, with knowledge that they are not isolated.

- **Jane Rhyder, NE Support Group Co-ordinator**





Grand luncheon - book now!

It's on again, the Scleroderma Victoria Grand Hotel luncheon to recognise World Scleroderma Day and raise funds for valuable research.

Put June 30 at 12.30 pm in your diaries and come and join a day of fun, fine food and drink and help raise funds for our cause.

The Grand Hotel will again offer a rebate on all tickets sold which will go directly back to Scleroderma Victoria for research funds.

Our Scleroderma Victoria Ambassador Dyson Heppell will welcome guests on the day.

There will be a silent auction of goods and services also.

The day includes a four-course lunch with matching wines for only \$120 per person.

Vegetarian and gluten free options will be available.

The menu for the day at this award-winning Richmond Hotel will be as follows -

CANAPE

Taleggio & pea suppli with chive mayo

Vegetable skewer - GF

ANTIPASTO

Gnocchi in brown butter and sage

Caprese salad - GF

SECONDO

Braised beef cheeks, mashed potato & gremolata

Vegetarian Risotto - GF, V

DOLCI

Roast pear, spiced honey cake, toffee ice cream

Get in early and book a table as there are only limited spaces available.

Call Kirsty at The Grand on 9429 2530 and make a booking now.



Bendigo Mob

A wonderful and unruly mob rocked up for lunch in February for the start of 2018 Bendigo Scleroderma Support Group luncheons.

We arrive from far and wide. Special cheers to Gene and Amanda, Melbourne is a long way away. A stimulating year will be had by our enthusiastic group at the Marong Family hotel where we are welcomed like friends, our watering hole.

All are welcome. Contact 54 303 305. Mobile 0419 889894. Check Facebook for our next lunch. Further dates will be advised later.

All the best everyone - *Judy Browning*

Coming soon to Geelong - New Support Group

Janelle Blight has volunteered to become the Support Group Leader for a brand-new group in Geelong.

Janelle had often wondered if there were other people living in her area with Scleroderma who she could connect with.

When she was approached recently by Jennene Caton (Secretary of Scleroderma Victoria) she readily accepted the challenge to lead the new group. She is planning to hold the inaugural meeting in June to coincide with World Scleroderma Day.

If you are interested, please contact Janelle on 0413046110 or email dermageelong@gmail.com.

Details of the Support Group meetings will also be published on our website and Facebook page.



Scleroderma Australia President Gene Swinstead (second left) joined the Gippsland Support Group where he was welcomed by Support Group Leader Corrie Hemming (left) and members for lunch recently at the Leongatha RSL.



Mornington/Westernport has welcomed its new Support Group Leader, Louise Inglese. Louise is pictured left being handed the "sunflower baton" by former Leader Annette Gaiardo at a recent get together.



Scleroderma Victoria member Dee Lynam addressed members of the Pakenham CWA branch and visitors from the West Gippsland group recently about Scleroderma.

Dee (left) received fantastic feedback regarding her talk and admiration for her positive outlook. Thanks to Dee Scleroderma Victoria has been chosen as the West Gippsland CWA group project for 2018!

The packets of seeds and pens that Dee took with her all sold out quickly and they are also donating the proceeds of the raffle and trading table to Scleroderma Victoria.

Thank you Dee for sharing your story and raising awareness and funds for Scleroderma Victoria.

Grapefruit juice interaction with drugs can be deadly



More prescription drugs are on the market that can interact with grapefruit juice with potentially serious effects including sudden death, Canadian doctors warn.

David Bailey, a clinical pharmacologist at the Lawson Health Research Institute in London, Ontario, discovered the interaction between grapefruit and certain medications more than 20 years ago. Since then, he said, the number of drugs with the potential to interact has jumped to more than 85.

Grapefruit juice is known to interact with some types of medications, leading to an overdose hazard.

Bailey reviews new product monographs and prescribing information for the Canadian Pharmacists Association and keeps a close eye on those with the potential to produce serious adverse reactions.

"What I've noticed over the last four years is really quite a disturbing trend, and that is the increase in the number of drugs that can produce not only adverse reactions but extraordinarily serious adverse drug reactions," Bailey said. "Between 2008 and 2012, the number of drugs in the list has gone from 17 to now 44."

Many of the drugs are common, such as some cholesterol-lowering statins, antibiotics and calcium channel blockers used to treat high blood pressure. Others include agents used to fight cancer or suppress the immune system in people who have received an organ transplant.

People older than 45 buy the most grapefruit and take the most prescription drugs, making this group the most likely to face interactions, researchers said in an article published in a recent issue of the Canadian Medical Association Journal, titled "Grapefruit-medication interactions: forbidden fruit or avoidable consequences?"

Older adults also tend to be less able to compensate when faced with excessive concentrations of drugs compared with young and middle-aged people — another reason that those over 45 seem to be particularly vulnerable, they added.

"Taking one tablet with a glass of grapefruit juice is like taking 20 tablets with a glass of water," Bailey said. "This is unintentional overdosing. So, it's not surprising that these levels go from what we call therapeutic to toxic."

Of the 85 known drugs that interact with grapefruit, 43 can have serious side-effects, including sudden death, acute kidney failure, respiratory failure, gastrointestinal bleeding and bone marrow suppression in people with weakened immune systems.

The authors noted that all sources of grapefruit — the whole fruit or 200 mL of grapefruit juice — and other citrus fruit such as Seville oranges (often used in marmalade), limes and pomelos can lead to drug interactions.

Why drug labels say 'Do not take with grapefruit juice'

Researchers advised that the affected drugs should not be consumed with those fruits. They also suggested noninteracting alternatives that could be prescribed.

But the authors can't say how big a problem the interactions are because of a lack of awareness. Health-care professionals might not be aware of the possibility to check into it and patients may not volunteer the information, Bailey said.

The researchers want to get the word out that the interaction can occur even if someone eats grapefruit or drinks the juice hours before taking a drug, such as downing the drink at breakfast and taking the medication after dinner.

Previously published reports showed that drinking a 200-mL glass of grapefruit juice once a day for three days produced a 330 per cent increase in the concentration of simvastatin, a commonly used statin, in the bloodstream compared with taking the medication with water.

The paper's authors said that the interaction doesn't apply to classes of drugs but to particular medications with three key characteristics:

- The drugs are taken orally.
- The percentage of the drugs absorbed or "bioavailable" is very low to intermediate.
- The drug is metabolized by an enzyme called cytochrome P450 3A4.

Patients can look for the criteria in the product monograph or prescribing information for a drug under "clinical pharmacology."

In theory, the batch, storage conditions and white versus pink type of grapefruit might influence the size of the interaction but the researchers said that hasn't been studied in detail.

Citrus fruits that interact contain active ingredients called furanocoumarins that irreversibly block the drug metabolizing enzyme.

Selected drugs that interact with grapefruit:

Anti-cancer

- Crizotinib.
- Dasatinib.
- Erlotinib.
- Everolimus.
- Lapatinib.
- Nilotinib.
- Pazopanib.
- Sunitinib.
- Vandetanib.
- Venurafenib.

Anti-infective

- Erythromycin.
- Halofantrine.
- Maraviroc.
- Primaquine.
- Quinine.
- Rilpivirine.

Anti-cholesterol

- Atorvastatin.
- Lovastatin.
- Simvastatin.

Cardiovascular

- Amiodarone.
- Apixaban.
- Clopidogrel.
- Dronedarone.
- Eplerenone.
- Felodipine.

- Nifedipine.
- Quinidine.
- Rivaroxaban.
- Ticagrelor.

Central nervous system

- Alfentanil (oral).
- Buspirone. Dextromethorphan.
- Fentanyl (oral).
- Ketamine (oral).
- Lurasidone.
- Oxycodone.
- Pimozide.
- Quetiapine.
- Triazolam.
- Ziprasidone.

Gastrointestinal

- Domperidone.

Immunosuppressants

- Cyclosporine.
- Everolimus.
- Sirolimus.
- Tacrolimus.

Urinary tract

- Darifenacin.
- Fesoterodine.
- Solifenacin.
- Silodosin.
- Tamsulosin.



RAISING FUNDS

... by the hair of my chinny, chin, chin



As the old saying goes “there are more ways to skin a cat”. Well there are more ways to raise funds too!

As a Sunflower Hero, Michael Papworth found a novel way of raising funds for Scleroderma Victoria.

In January 2017 he decided to grow his beard for 12 months! To boost his fundraising efforts, he also held a sausage sizzle at the Bunnings store in Pakenham in December 2017.

“My wife’s aunty Louise (pictured right with Michael) was recently diagnosed with Scleroderma and I wanted to help raise money to help find a cure,” said Michael. There isn’t a lot of funding for the disease, so I was hoping to raise at least \$5000 to put towards finding a cure.

His big shave finally occurred on January 19 this year. By this time Michael had raised \$5700 via the Everyday Hero website.

Michael says it was sad to see his beard go. “It’s been with me through many meals and has been home to some yummy late night left overs.

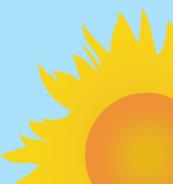
“I was sad and looking a lot younger come that Friday when we held a little gathering where the local barber shaved my beard off, clean to the skin”!

Scleroderma Victoria has used the funds raised by Michael to purchase another new portable oxygen concentrator with excess money going to research. These machines help scleroderma patients with their breathing. They are very expensive, so Scleroderma Victoria buys them and loans them out for a peppercorn rent.

Thank you, Michael, you are a true Sunflower Hero.

Scleroderma Victoria now has five machines to loan out to our members at a very low cost.

If you, or someone you know, needs a machine please call Jennene at the office on 92883651 (please leave a message).



It's time for flu vaccination!

Following the horrific flu season of 2017 - which killed more than 1000 Australians - it pays to protect yourself ahead of the winter months. This is particularly important for people who suffer from Scleroderma because of their compromised immunity.

Last year saw 250,000 confirmed cases of flu - the highest on record and almost three times the number of cases seen in 2016.

"The 2017 flu season was the worst we've seen since the 2009 pandemic. Not only that, but in much of Australia it began a month earlier than anticipated and also peaked for longer than usual," says Dr Aifric Boylan, CEO of Qoctor, the quick online doctor.

Dr Jamie-Lea Whyte from VirtueVax says this year could be particularly interesting, as international attendees of the Commonwealth Games will bring with them northern hemisphere influenza strains in one swift swoop.

Flu season in Australia begins in June and continues until the end of September and October. While the flu risk is currently 'minimal' according to Health Direct, these tips will help you get ahead of the oncoming flu season.



GET VACCINATED

Following the tragic flu-related deaths of 2017, the Australian government has announced two new 'turbocharged' flu vaccines will be available to over 65s, pregnant women and some Aboriginal and Torres Strait Islander people for free from April.

If you don't fit into one of these groups, it's still worth getting the vaccine.

The best time to get immunised is in early autumn when the vaccine becomes available, says Dr Aifric, so that your body can build immunity before the flu season hits. Be careful not to get the vaccine more than six months before the end of flu season, however, as your immunity will wane and leave you vulnerable during peak flu season.

"Some people may find they get a sore arm or feel a bit tired or achy after having the flu vaccine and may prefer to get it just before the weekend or on a non-work day," Dr Aifric says.

Serious side effects are extremely rare, and Dr Jamie-Lea assures me that - despite the common misconception - you cannot catch influenza from the vaccination itself.



HYGIENE

Although the vaccine is the most effective way to safeguard yourself from the flu, winter is a hotbed of illnesses and prioritising your health during the season can give you a better chance at fending off some of the nasty bugs being passed around.

Hygiene should be your number one health focus - always wash your hands with soap and water or hand sanitiser before eating and drinking and avoid touching your mouth, nose or eyes throughout the day, as this is how viruses and bacteria enter our bodies.

Dr Aifric also advises avoiding people who have flu-like symptoms where possible and, if you're sneezing or coughing, using a tissue or shielding your face in your elbow.

KNOW THE SYMPTOMS

People often refer to a particularly nasty cold as the flu, but there's a big difference between the two. Colds are very common viruses, with symptoms that are usually milder and different to those associated with the flu.

If you're suffering from a mild to moderate case of influenza, you'll likely experience a runny nose, fever, sore throat, dry cough, muscle aches and fatigue.

WHAT SHOULD YOU DO IF YOU GET THE FLU?

If symptoms are mild, the doctors' advice is to stay at home, rest up and drink plenty of fluids. "Paracetamol is usually recommended for aches and pains and nasal sprays or decongestants may ease a runny nose," Dr Aifric says.

"Patients with true influenza cases are often too unwell to leave their bed, especially in the first few days and rest is exactly what their bodies need," says Dr Jamie-Lea. "As this is a viral illness, expect things to take their course over one to two weeks."

Antibiotics aren't effective in combating influenza, because it's a viral rather than a bacterial infection.

WHEN TO CALL THE DOC!

If your symptoms are worsening over time and not improving slowly each day, or if you have pre-existing medical issues like scleroderma, asthma, pregnancy or diabetes, then you should see a doctor.

'Red flag' symptoms that mean immediate medical attention is needed " include shortness of breath, dizziness or faintness, confusion, vomiting and sharp chest pains, which can indicate pneumonia."

Stay safe this flu season, get vaccinated!

Meet our Secretary / Admin Assistant - Jennene Caton



Jennene is often the first point of contact for Scleroderma Victoria. She operates our office at St Vincent's Hospital every Tuesday morning between 10am - 12pm.

She responds to phone calls and emails from members and newly diagnosed people seeking advice and information.

She maintains our stock of Portable Oxygen Concentrators, ensuring that they are serviced and ready to help our members.

Her other duties include processing and banking all donations and membership subscriptions and maintaining our membership database. In her role as Secretary, she keeps the committee on track by producing agendas taking the minutes at each meeting.

The Secretary is also the Public Officer for Scleroderma Victoria and there are annual reporting requirements for Consumer Affairs that Jennene is responsible for. Jennene has also written several successful grant applications on behalf of Scleroderma Victoria which total over \$20,000.

Why did you become Secretary / Admin Assistant for Scleroderma Victoria?

For the same reason that I joined Victoria Police in 1988, to help people and make a difference in our Community.

In 2014 I retired from Victoria Police due to Scleroderma, at the rank of Senior Sergeant, after a career spanning 26 years. After spending the first nine months on the couch at home, recovering and watching Grey's Anatomy seasons 1 - 9, I thought there must be something else I can do! Plus, I am very much a "people person" and it was getting very lonely on the couch.

My career with Victoria Police had given me many skills which I felt were a shame not to keep using. Although no longer able to direct traffic and chase after bad guys, I felt I could make a difference in other ways. I met with the (then) President of Scleroderma Victoria, Mr Gene Swinstead and volunteered my services. Gene invited me to become part of the committee in 2014 and I have been the Secretary since March 2015.

How long have you been Secretary / Admin Assistant?

Secretary since March 2015, and I have been the Admin Assistant since March 2016.

What is the best thing about being Secretary / Admin Assistant?

I find it very rewarding to help others. To receive thanks from someone we have loaned a portable oxygen concentrator to, or from someone I have helped over the phone is such a buzz for me. Plus, it helps me to forget my own issues for a while.

Scleroderma has taken so much from me, but there is still a lot I can do. I am also exposed to the generous and giving side of humanity, something that was a bit lacking in my previous career! I have also made many new friends.

What is the worst thing about being Secretary / Admin Assistant?

Can't think of anything right now, I really enjoy this role.

Name your top tips for a Secretary / Admin Assistant

Be super organised and ask for help when you need it.

What is your passion outside of being Secretary / Admin Assistant?

My wonderful supportive family and my little dog Tessie. I also enjoy reading, knitting and crochet.

'Living Statues' find support in each other

by ESTHER LAUAKI
STAR Newspapers

Life's hard for Yvonne Hoffmann and Janene Caton. Both live with a rare disease they say is turning them into living statues.

The two Melton women are among 6000 Australians living with scleroderma, or systemic sclerosis, a chronic auto-immune disease that causes the hardening of skin and connective tissue all over their bodies.

Mrs Hoffman, 63, and Mrs Caton, 51, are raising awareness for World Scleroderma Day on June 29. They also meet monthly with other sufferers at the Westies Support Group in Caroline Springs.

"It eventually means you can't move. You can't bend to put on socks, raise your arms to comb your hair - and the connective tissue surrounding your organs, eventually that will harden too. I've only recently been able to press my hands together to clap and I celebrate those little things," Mrs Caton said.

"It feels like your skin is two sizes too small for your body, like you're being shrink-wrapped. I have very few wrinkles on my face and people often tell me, 'you've never looked better'," Mrs Caton said.

Mrs Hoffman owned a business, worked in retail and supervised disabled children before her diagnosis six years ago.

"I lost the use of my hands, so life's bloody hard. My husband and children have to do everything for me. I can't cook or clean with these hands."

Mrs Caton recently retired from Victoria Police after 26 years.

"Victoria Police was so good to me and they allowed me to keep working a desk job," she said.

"I was doing intelligence work, which was very fulfilling, for about eight years until my body didn't allow me to do that anymore.

"You have to give up everything. Family and friends are what keeps you going and the friendships that I've made in the Melton community have taught me that, if you need help, you can ask. The kindness of strangers in the community is overwhelming."

The Westies Support Group of women and men with scleroderma meets at West Waters Hotel in Caroline Springs once a month.



To donate or for information, go online at www.sclerodermavictoria.com.au
Republished from STAR newspaper.

Jennene Caton and Yvonne Hoffman want to raise awareness about Scleroderma.

Picture: Joe Mastroianni

Gift to fund Research

Through the generosity of former Scleroderma Victoria President Graham Copsey, we are pleased to announce a research project to be carried out by the Australian Scleroderma Interest Group (ASIG).

Mr Copsey was one of the founding members of Scleroderma Victoria serving on the Committee for many years. He held many positions including President and Public Officer.

He left Scleroderma Victoria a wonderful and generous gift in his will which, after consultation with the Doctors at the Australian Scleroderma Interest Group (ASIG), has been used to fund a research project in his name.

The project is on Reducing the risk of cancer in scleroderma: a data linkage study.

A number of studies have shown an increased risk of certain cancers in scleroderma.

This study entails 'linking' the ASIG database to the Australian Cancer Registry in order to quantify the risk of cancer in scleroderma relative to the general population and to determine risk factors for the development of these cancers.



Graham Copsey's daughters Jane, Sarah and Sue hand over their father's cheque to ASIG Doctors Susannah Proudman (left) and Jo Sahhar.

The ultimate goal of this study is to identify ways in which cancer risk can be reduced and patient outcomes improved in scleroderma.

If you would like to leave a bequest to Scleroderma Victoria in your will, please contact Jennene at the office on 92883651 (please leave a message). We can also provide funeral donation envelopes.

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people, this is only mild and does not require specific treatment.

ASIG has shown that the amount of lung involvement on high resolution CT lung can predict which people are going to have more severe disease and need therapy. ASIG has also shown that the rate of loss of lung volume on lung function tests can also identify a group of people who are likely to need treatment for their lung disease.

The current work of ASIG is focussed on trying to identify some blood markers ('biomarkers') that might predict if a person is likely to develop lung disease and how severe it may be.

Any part of the gastrointestinal tract can be affected by scleroderma, including the oesophagus, stomach, small and large bowel. Scleroderma can affect the muscle of all of these parts leading to very slow movement of food through the stomach and bowel. As a consequence of this slow movement, people have excessive numbers of bacteria in the bowel, resulting in bloating, diarrhoea, malabsorption and weight loss.

Studies have shown that people with scleroderma have a different range of bacteria in their bowel when compared with healthy controls, with a particular pattern being associated with more extensive skin involvement.

This has led researchers to speculate that restoring a more normal pattern of bowel bacteria might possibly be a treatment not only for scleroderma bowel involvement, but also for scleroderma in general. However, a good deal more research into this area is needed. Current studies of probiotics and cyclical antibiotics to treat bacterial overgrowth in scleroderma gut are under way.

Autologous (meaning from 'self') stem cell bone marrow transplantation has come under the spot light recently with the recent publication of the SCOT clinical trial. All of SCOT and two other trials (ASTIS and ASSIST) previously published, have shown a benefit in terms of skin softening and improvement in lung function in a select group of scleroderma patients who do not have other serious organ involvement. However, this improvement is at the expense of relatively high risk of serious complications and even death in some people.

A/Prof Nikpour explained that at this stage, more needs to be known about the optimal selection of people and the best procedure for preparing people for bone marrow transplantation in order to improve the outcomes.

As we learn more about the abnormal processes involved in the development of scleroderma, there is hope emerging of developing

more 'targeted' therapies that address specific disease features.

Several treatments are currently in phase III clinical trials including the 'biologic' agents rituximab (being trialled in scleroderma arthritis and ILD) and tocilizumab (in scleroderma skin involvement), the 'antifibrotic' agents nintedanib (for scleroderma ILD) and pirfenidone (in scleroderma ILD and skin involvement), and the selective cannabinoid receptor blocker lenabasum (in early diffuse scleroderma skin involvement).

Over the past 10 years, the research achievements of ASIG have placed Australia at the forefront of global research in this complex disease.

Large international collaborative groups led by ASIG researchers continue to work on determining ways of improving the quality of life of those living with scleroderma, in the hope of one day having a cure.

This research would not be possible without the contributions of many people with scleroderma to the Australian Scleroderma Cohort Study database and biobank, their willingness to take part in clinical trials, fund raising and advocacy.

Over the next 10 years of ASIG, people with Scleroderma and ASIG researchers will remain important partners in the pursuit of effective treatments in this difficult disease.