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Susanna Proudman

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# SCLERODERMA connections

PATIENT NEWS

EDITION 3: MAY 2011



## greetings,



Welcome to old and new readers of Scleroderma Connections. I am delighted that, for the first time, this issue is to be distributed to general practitioners as well as specialists who care for patients with systemic sclerosis (SSc). And as usual, there is a patient-focused version for patients.

One of the joys of being involved in an initiative such as ASIG, is the opportunity to take time out from working at the "coal face" to meet with colleagues who share a desire to understand better, diseases such as SSc. On April 15th, ASIG members from centres around Australia met at St Vincent's Hospital in Melbourne to discuss collaborative projects

**"ASIG was established in 2007 in 12 centres around Australia with the primary aim being to provide a screening service to patients and their doctors, for the cardiopulmonary complications of SSc: pulmonary arterial hypertension (PAH) and interstitial lung disease (ILD)."**

By way of introduction, Scleroderma Connections is prepared by members of the Australian Scleroderma Interest Group (ASIG) to keep patients and their health care professionals informed about SSc and ASIG's activities, especially the Australian Scleroderma Screening Programme. This was established in 2007 in 12 centres around Australia with the primary aim being to provide a screening service to patients and their doctors, for the cardiopulmonary complications of SSc: pulmonary arterial hypertension (PAH) and interstitial lung disease (ILD).

Patients are referred by their rheumatologists for annual assessment with a combination of screening examinations and tests including echocardiogram and pulmonary function tests. Those who are determined to be at high risk, are offered formal diagnostic testing with high resolution CT scanning of the chest (for ILD) and/or right heart catheter (for PAH). Timely diagnosis offers the best opportunity for early therapy and improved outcomes for these potentially life-threatening complications. Of course, this is intended to be an adjunct to the model of shared care by GPs and community rheumatologists, not to replace it.

using the valuable database that is collated from the patients in the Screening Programme. Read more about the workshop elsewhere in this issue.

In this issue, find a profile on Dr Jane Zochling and her staff at the hard-working screening centre at Menzies Research Institute, Tasmania and an introduction to the new SSc fellows.

Instead of the workshop, the patient-version of the issue features a section on "handy tips" from Hayley O'Sullivan, occupational therapist.

And don't forget World Scleroderma Day on June 29th.

If you would like to learn more about ASIG and our activities, contact details for our wonderful project manager, Jill Byron and individual centres are located on the back of the newsletter.

Happy reading!

*Susanna*

**Susanna Proudman**  
ASIG Chair

## World Scleroderma Day

June 29



### Oral Presentation on Wound Care RHPA Annual Meeting

Barbara Gemmell, the Scleroderma and PAH nurse at St Vincent's Hospital, will be giving a talk entitled **"A 16 month audit of wound care in scleroderma patients"** which will highlight the need for better understanding of types of wounds patients have and the best way dressings can optimise healing and relieve pain.

The presentation is on **Sunday 15th May, at 3pm.**



## profile.



Dr Jane Zochling and Trish Lewis

# Menzies Research Institute

## TASMANIA

The Tasmanian ASIG screening program is led by Dr Jane Zochling. Jane is a consultant rheumatologist, combining her private and hospital work with a strong commitment to research through her role as the Butfield Research Fellow at the Menzies Research Institute Tasmania.

Her interest in scleroderma research began with the Tasmanian Systemic Sclerosis Epidemiology (TASSiE) study, and led to her collaboration with the national group ASIG. She also has a strong interest in research into ankylosing spondylitis.

Trish Lewis assists Jane as research assistant in a general management role. She is available at Menzies on 6226 7776 (Mon to Thurs) or email [lewisp@utas.edu.au](mailto:lewisp@utas.edu.au) Jane and Trish currently see study participants at Menzies on a Thursday morning, with some assistance by the RHH

Rheumatology Registrar, Dr Jo Hall and Resident, Dr Emma Mitchell, who also have a special interest in scleroderma. Visits to the north and northwest of the state are made 6 monthly.

There are currently 158 patients throughout Tasmania who are a part of the ongoing screening program, the majority being seen annually. The program has already shown success in identifying early development of PAH in several patients allowing for immediate intervention. Jane's own Tasmanian study also involves a comparison group of participants who have Raynauds only.

## tips.

# Handy Tips for 2011

With summer never really arriving this year and the months passing by so quickly I thought it might be worthwhile to review the presentation that I gave a few years ago at the Victorian conference so we can prepare our hands for the winter months.

### Gloves

Thermoskin gloves provide an excellent source of heat to the hands. The thermal layer that lines these gloves makes them comfortable and warming. They also allow for that circumferential pressure which can help to ease aching joints by providing support. The heat set grip on them allows them to be used for most functional activities as well. In winter I ride my bike with them on. It is important though that you are fitted with the right size of glove as they can cause circulation issues if too tight.

### Finger sleeves

Silicone digi caps/sleeves can provide similar support and relief as mentioned in the gloves section. They are great for single finger issues and for stopping the finger joints from being knocked as the silicone padding in them acts like a little shock absorber. They again need to be fitted properly and cannot be worn on an open wound.

### Paraffin Wax Bath

These are fantastic for a number of reasons. They provide deep moisturising heat to the hand and relief from pain. If you respond well to heat, this is a must. All of my patients who use the wax bath in my rooms end up purchasing them for their home use. While the heat can help soften skin and warm the joints, it can also assist you in improving your range of motion due to the many benefits of heat in helping to soften tissue and decrease pain sensors. The best place that I have recently purchased these from for patients is [www.amazon.com](http://www.amazon.com). Just type in "paraffin wax bath". My patients have been getting them for around AUS\$50.00 and that has included the bath, wax and delivery. You can try ebay and department stores also.

### Finger splints

Can assist with the healing of finger wounds by offering a covering over the fingers that is still breathable, comfortable, and can come on and off.

I have also used longer splints to assist with contractures that occur in patients fingers. The main aim of the splint is to decrease the amount of contracting at a joint rather than increasing. These bigger splints can take time and patience to get right

### Other Hot tips:

- Keep hand well moisturised with products that are lanolin based. The hemp hand cream from the body shop is great
- Avoid working in water too much as this will dry the skin out. Use gloves whenever possible
- Drink water to keep well hydrated
- Visit your local daily Independent Living Centre as they have a great arrangement of aids and appliances that can assist you around the home and help you maintain your independence. Use this link: <http://www.ilcaustralia.org/home/default.asp>

Hand Therapists are all throughout Australia and can assist you with all that has been mentioned above and more. If you would like to see a Hand Therapist please log on to this link

<http://www.ahata.com.au/site/index.cfm?display=248200> and follow the instructions.

It would be worthwhile chatting to your GP about the EPC program which covers patients with a chronic disease or illness for 5 visits a year to see an allied health professional. Medicare will cover around 70% of the cost. I would encourage you all to do this.

I wish you all a happy and healthy 2011.

### Hayley O'Sullivan

Hand / Occupational Therapist  
St Vincent's Hospital, Melbourne

## research.

# Donations to the ASIG Research Program

ASIG would like to thank patients and their families who have generously donated to the ASIG research program. The money is used to:

- Fund blood sample research which we hope will help to explain why some people develop the serious complications associated with scleroderma - \$30 would cover the cost of one sample.
- Maintain the national database, a vital part of rare disease research - \$250 would provide the hardware to link one researcher to the online database.
- Contribute to a scholarship for a PhD student - Rheumatology Consultants or Registrars who choose a career in research undertake a three year research degree. ASIG is committed to sponsoring one student per year who is interested in focusing on scleroderma and contributing to a better understanding of this rare disease.

If you would like to make a donation to ASIG you could:

- Send a cheque made payable to "Australian Rheumatology Association" to:  
ASIG  
C/O Australian Rheumatology Association  
ARA Secretariat  
145 Macquarie Street  
SYDNEY, NSW 2000  
\* Be sure to include a note stating that the funds are to go into the ASIG research account and include your name and address.
- Make an Electronic Funds Transfer (EFT) to:  
Account Name: Australian Rheumatology Association  
Bank: ANZ  
BSB: 012-310  
Account No: 2260-41374  
Description: ASIG research  
\* Also send an email to the ASIG Project Manager, Jill Byron ([jill.byron@svhm.org.au](mailto:jill.byron@svhm.org.au)) confirming your payment.

# Research Team News



Dr Mandy Nikpour and Dr Wendy Stevens were also pleased to welcome Dr Owen Moore for a 12 month Scleroderma fellowship at St Vincent's Hospital, Melbourne. Owen is a UK trained doctor who has just completed his rheumatology training in Northern Ireland. In recent years he has completed a Masters Degree in rheumatology at Oxford University. He will be working as a Scleroderma Fellow at St Vincent's Hospital over the next year on an Interstitial Lung Disease Project partly funded by a grant from Scleroderma Australia. His project involves reading scans of patients who have ILD, so patients or centres may be contacted by Owen to arrange collection of the scans.

In February ASIG welcomed Dr Vivek Thakkar, the ASIG Fellow for 2011. Vivek has enrolled in a PhD at The University of Melbourne and he will be generating reports from the ASIG research database.

Further information about ASIG can be found at:

<http://rheumatology.org.au/rheumatologists/asig-public.asp>



## contact.

### RESEARCH QUERIES

Jill Byron, Project Manager  
Ph: 03 9288 3986 Email: [jill.byron@svhm.org.au](mailto:jill.byron@svhm.org.au)

## AUSTRALIAN SCLERODERMA SCREENING CENTRES

### Western Australia

ROYAL PERTH  
Janet Roddy &  
Madelynn Chan  
Ph: 08 9224 1310

### South Australia

ROYAL ADELAIDE  
Susanna Proudman  
Ph: 08 8222 5190

QUEEN ELIZABETH  
Catherine Hill  
Ph: 08 8222 6688

### Queensland

SUNSHINE COAST  
RHEUMATOLOGY,  
MAROOCHYDORE  
Peter Nash & Louisa Voight  
Ph: 07 5443 1033

### New South Wales

JOHN HUNTER,  
NEWCASTLE  
Gabor Major &  
Glenn Reeves  
Ph: 024921 3000

ROYAL NORTH SHORE  
Les Schrieber  
Ph: 02 9926 7351

ST GEORGE SYDNEY  
Allan Sturgess  
Ph: 02 9113 2670

ROYAL PRINCE ALFRED  
Peter Youssef  
Ph: 02 9515 9337

### Australian Capital Territory

CANBERRA  
RHEUMATOLOGY  
Kathie Tymms  
Ph: 0437 595 334

### Victoria

ST VINCENT'S  
Wendy Stevens  
Ph: 03 9288 3983

MONASH MEDICAL  
CENTRE  
Joanne Sahhar  
Ph: 03 9594 3566

### Tasmania

MENZIES RESEARCH  
INSTITUTE  
Jane Zochling  
Ph: 03 6226 7776



*Australian  
Rheumatology  
Association*

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[www.rheumatology.org.au](http://www.rheumatology.org.au)