



WELCOME
Susanna Proudman

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Menzies Research Institute

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SCLERODERMA connections

EDITION 3: MAY 2011

SSC SCREENING CENTRE UPDATE



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



ASIG abstracts accepted for ARA Conference

Posters:

Mortality and Cause of Death in an Australian Systemic Sclerosis Cohort
Mandy Nikpour

Frequency, Clinical Characteristics and Risk Factors for Digital Ulcers in Systemic Sclerosis
Wendy Stevens

Prevalence of Coronary Artery Disease
Gene Ngian

Survival in an Australian Cohort of patients with Connective Tissue Disease Associated PAH
Gene Ngian

Mycophenolate Mofetil (MMF) in Scleroderma (SSc) associated Interstitial Lung Disease (ILD) and Skin Disease
– The Australian Experience
Suren Jayaweera

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 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.

workshop.

PAH/ILD Workshop

15th April, St Vincent's Hospital, Melbourne



Left to right: Gene Ngjan, Peter Youssef, Nicole Goh, Vivek Thakkar, Tamera Corte, Suren Jayaweera, Janet Roddy, Jenny Walker, Mandy Nikpour, Susanna Proudman, Wendy Stevens, Pravin Hissaria and Owen Moore.

This one day workshop was attended by rheumatologists from ASIG centres around Australia including the inaugural ASIG research Fellow, Dr Vivek Thakkar and Dr Owen Moore, St Vincent's Fellow, who are undertaking important projects using data from the ASIG database. We also welcomed respiratory physicians, Drs Nicole Goh and Tamera Corte, both of whom have worked with Professor Athol Wells, one of the world experts in interstitial lung disease in systemic sclerosis (SSc), at the Brompton Hospital in London, UK. They have built up impressive expertise in this area and it is a pleasure to have them as collaborators.

The goals of the workshop were:

1. To introduce the new fellows and collaborators to ASIG
2. To exchange information about pulmonary arterial hypertension (PAH) and interstitial lung disease (ILD) in terms of literature reviews, previous experience and plans for future studies.

Nicole Goh, who now works at the Austin Hospital in Melbourne, summarised her work using Prof Well's scoring system for ILD using CT scanning and pulmonary function tests. Tamera, who had travelled down from Royal Prince Alfred Hospital in Sydney, presented her work on predictors of PAH in patients with ILD. Both presentations stimulated much discussion about possible applications in

studies of patients in the ASIG database. Vivek gave a comprehensive summary of predictors of outcome in patients with SSc-related PAH as an introduction to his project in this area and Owen spoke about his plans for a detailed study of ILD in the patients in the ASIG database.

It was also a great opportunity to hear updates on smaller studies which are nearing completion. Gene-Siew Ngjan presented her new data on outcomes in Australian patients treated for connective tissue related-PAH. Suren Jayaweera's presentation on the Australian experience with mycophenolate in patients with SSc also led to valuable discussion.

It was clear by the end of the day, after other studies were discussed such as Janet Roddy's talk on ultrasound in skin scoring in SSc, that there are many opportunities for original and exciting work arising from the hard work people continue to put into the ASIG programme.

Thanks must go to the ASIG project manager, Jill Byron for arranging the workshop and to Drs Wendy Stevens and Mandy Nikpour who have supervised most of the work to date.

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) confirming your payment.

Research Team News



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.

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.

Further information about ASIG can be found at:
<http://rheumatology.org.au/rheumatologists/asig-public.asp>



contact.

RESEARCH QUERIES

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*Australian
Rheumatology
Association*

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