EDITION 5: MAY 2012

SSC SCREENING CENTRE UPDATE

connections: SCLERODERMA

greetings,

After more than five years' work, it is very rewarding to see our Australian Scleroderma Cohort Study mature into an invaluable tool for understanding clinical and pathological aspects of this disease. In early February, some of our ASIG members attended the Second Scleroderma World Congress where we had a thrilling response to the presentations describing our work. Read on for the report from this Congress which highlights the achievements of the ASIG and St Vincent's Hospital Fellows.

Another of the presentations describing preliminary results from genetic studies in our patients, was given by Dr Jane Zochling. In the next few months, we hope to extend these studies to other patients in the programme if they have given informed consent for this. Similarly, Dr Vivek Thakkar will be expanding the NT-pro-BNP study to the larger cohort, to validate his preliminary work using a blood test for NT-pro-BNP to stream-line the process of screening for pulmonary arterial hypertension. Hence, there is a renewed focus on collecting biological samples from patients and transferring them to Adelaide, where they are stored and managed by staff of The Queen Elizabeth Hospital Rheumatology Unit. A new "biobank" database for managing these samples is currently in development.

Dr Thakkar is also to be congratulated on being awarded a NHMRC post-graduate scholarship to complete his studies. We plan to offer the ASIG fellowship again in 2013. We are delighted to announce that Scleroderma Australia has made a major donation towards the funding of this fellowship which will be referred to as the ASIG-Scleroderma Australia Fellowship. I would like to express our heartfelt thanks to all the members of Scleroderma Australia and their president, Robyn Sims, for their hard work in raising these funds and their wonderful generosity in offering us this exceptional donation.

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On a sadder note, our Project Officer, Dr Jill Byron, stalwart of all ASIG activities, is leaving us for new pastures. We will remain forever grateful to her for her skills and guidance which were instrumental in bringing ASIG and the Australian Scleroderma Cohort Study to life from the earliest days onwards. We wish her every success in her next role.

Susanna

Susanna Proudman
ASIG Chair

screening.

Access to screening for cardiopulmonary complications of systemic sclerosis

Current international guidelines recommend that all patients with systemic sclerosis (SSc), irrespective of disease subtype or duration, be screened annually for pulmonary arterial hypertension (PAH).

This complication occurs in nearly 12% of Australian patients with SSc. The ASIG algorithm uses annual echocardiogram and pulmonary function tests as well as comprehensive clinical assessments to ascertain risk of PAH and to identify progressive interstitial lung disease.

Access to screening for cardiopulmonary complications of scleroderma is freely available at all ASIG centres around Australia (listed on the back of this newsletter) and is intended to complement usual rheumatology care.

If you would like to learn more about referring your patients with SSc for screening, please contact Asig.PROJECT@svhm.org.au.

ASIG
AUSTRALIAN SCLERODERMA INTEREST GROUP

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

contact.

RESEARCH QUERIES
Ph: 03 9288 3986
Email: asig.PROJECT@svhm.org.au

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Australian Rheumatology Association

www.rheumatology.org.au

This ASIG publication is supported through an unrestricted educational grant from Actelion

profile.

Royal Prince Alfred Hospital

The Pulmonary Hypertension Clinic at Prince Alfred is a true multidisciplinary clinic

Management of patients with Pulmonary Arterial Hypertension is highly specialised and can require input from multiple medical and allied health professionals at a major tertiary referral centre.

For a number of years now, patients that are referred to the Pulmonary Hypertension Clinic at Royal Prince Alfred Hospital have been able to benefit from a true multi-disciplinary approach to their treatment.

Patients who attend the clinic are assessed by a cardiologist (Professor David Celermajer), respiratory physicians (Assoc Prof Paul Torzillo and Dr Tamera Corte), Immunologist (Dr Roger Garsia) and Rheumatologist (Assoc Prof Peter Youssef).

This approach where the patient is seen at each consultation by the whole of the multidisciplinary team is unique. It facilitates a patient specific management plan that considers a wide range of factors in the treatment of a highly complex disease.

The coordination and balance of this busy clinic is the responsibility of Sr Dot Fowler (rheumatology clinical nurse specialist) whose main speciality remains rheumatology, but whose experience and knowledge is vital to the smooth running of the clinic.

Advanced Trainees are also given the opportunity to help assess patients in the clinic – providing training in what is a complex and varied disease state.

The clinic receives referrals from around New South Wales and provides a screening service for pulmonary hypertension in connective tissue diseases. Patients can be seen urgently if required.

research.

ASIG Research Output

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His research has shown that it is possible to utilise a short, simple grading system to assess the extent of systemic sclerosis lung disease on an HRCT chest; and that this grade is predictive of outcome. That is to say, extensive disease predicts poor outcome, and that this should act as a trigger for more aggressive therapy. Furthermore he has shown that, in the follow-up of patients with systemic sclerosis associated lung disease, pulmonary function tests are a reliable way to monitor for worsening disease. This work is now in manuscript form and has been submitted for publication.

Currently he is working on the bank of pulmonary function data from the ASIG database to ascertain whether it is possible to define a level of decline that should trigger closer monitoring, more investigations or treatment.

Owen's work has contributed to a greater understanding of risk factors of poor outcome in systemic sclerosis related lung disease. We appreciate his hard work and dedication and congratulate him on his success.

world congress.

2ND SYSTEMIC SCLEROSIS WORLD CONGRESS

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The presentations covered work that is at the vanguard of clinical research in systemic sclerosis and were very polished. They were all very well-received both in question time, as evinced by the quality and number of questions, and informally, when members of the Australian contingent were approached by various senior experts to discuss the work and future prospects for collaboration. The two talks given by the Fellows, Vivek Thakkar and Owen Moore, were selected by Dan Furst for inclusion in the clinical highlights session, a great honour for them and their supervisors, especially Mandy Nikpour and Wendy Stevens who have been outstanding mentors.

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Special mention should be made of Barbara Gemmell (Scleroderma/PAH nurse from St Vincent's Hospital in Melbourne) who gave a very accessible and informative invited presentation on Wound Care in a session on "Vascular complications" in the exceptionally well-attended Patient Programme.

These results are a credit to ASIG and a testament to the hard work of all our members.

research fellow.

ASIG–Scleroderma Australia Research Fellow for 2013

Expressions of interest are sought from MBBS graduates with an interest in research in systemic sclerosis (SSc).

The Australian Scleroderma Interest Group has established a national database to collect prospective clinical and investigative data from SSc patients. This forms the basis of the Australian Scleroderma Cohort Study and is a valuable resource for a range of research projects. The group invites expressions of interest from physicians who are interested in one of the following options:

- A 12 month fellowship, to coordinate the preparation of publications including literature review, data extraction and analysis, paper writing and manuscript preparation.

OR

- A fulltime student enrolled in a Masters of Philosophy, PhD, or Professional Doctorate.

The successful candidate would commence in February 2013 and receive supervision and support from experienced clinicians and researchers.

Option 1: The fellow would be employed fulltime for a period of 12 months. This position would suit any physician with an interest in developing research skills. A salary package of $50,000 will be offered.

Option 2: The student would be an Australian resident enrolled or planning to enrol in a fulltime graduate research degree. Funding would be according to NHMRC guidelines and may be tax exempt depending on the individual's circumstances. Initial funding is for the first year, to a value of $50,000 total package.

Queries should be addressed to:
The Chair of ASIG, Susanna Proudman,
sproudman@internode.on.net

Or the project co-ordinator,
Asig.PROJECT@svhm.org.au

Deadline for submissions is 8th June 2012
and should be emailed to:
Asig.PROJECT@svhm.org.au

SCLERODERMA connections

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PATIENT NEWS

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donations.

ASIG Research Program

Thank you to the family of the late Mrs Olga Garrao for their generous donation to the research fund.

Donations assist a number of our projects such as blood sample research, maintenance of the national database and funding of a PhD student. There are two ways to make a donation to the fund:

Cheques can be made out to "ARA-ASIG" and mailed to:

ASIG Project Officer
PO Box 296
Carlton South, VIC, 3053.

Electronic Funds Transfer (EFT) to:

Account Name:	ARA-ASIG
Bank:	CBA
BSB:	063-449
Account No:	1019 7446
Description:	ASIG research

Please send an email to ASIG.project@svhm.org.au to confirm your EFT.

Please note: Donations to ASIG cannot be claimed as tax deductions.

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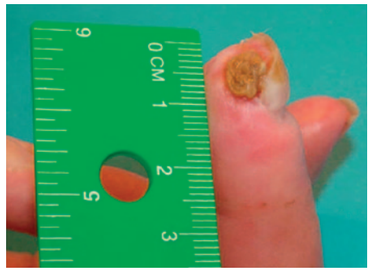
survey.

Patient wound survey



Scleroderma Australia is concerned about the cost of dressings to patients – ointments, coverings and bandages. To understand more about this considerable and unavoidable expense, they distributed a survey. A total of 32 people responded with average age 61 years. There were 29 women and 4 men. The largest number came from Victoria (64%) followed by NSW (30%) and one each from QLD and ACT.

The average age of onset of scleroderma ulcers in the group was 45 years. All but one respondent had ulcers on the hands/ fingers at some point. Other locations were feet/toes (34%), legs (19%), arms (6%), face (1 person). In the past year, 2 people had not had any ulcers, 2 reported too many to count and the rest had an average of 5. The average time for each ulcer to heal was estimated at 25 weeks with a large range, from 3 weeks to 3 years.

The average number of dressing changes per week was 7 (range 1-21). Two respondents noted that the frequency of changes decreased as the ulcer healed. The weekly cost of dressings was estimated at $40. This cost was on top of medication estimated at $35 per week. To estimate the annual cost of ulcer treatment for each person we multiplied the number of ulcers by the time taken to heal, by the number of dressings and the cost of dressings. It was a complex calculation so this is an indication only but it came to an average per year per patient of $2050.