

greetings,



After a long cold winter, at least in the southern parts of our country, we are looking forward to some warmer weather, although it seems to be even slower to arrive than usual!

It has been a tough year for people with Raynaud's phenomenon and scleroderma-related skin ulcers who must wonder at times if they will ever feel warm again. So at the time of writing, it is exciting to feel the onset of spring in the air, at last. What's more, it is also exciting to report that, after achieving some success with therapies for pulmonary arterial hypertension, pharmaceutical companies are interested in finding solutions to the troublesome problems of Raynaud's phenomenon and digital ulcers. It is early days but there is hope that one day, there will be new treatment options for these problems.

screening centres; in this issue, the centre at Monash Medical Centre in Victoria.

The ideas that underpin new therapies often arise in the laboratories of scientists whose names may not be familiar to the doctors who prescribe them, let alone the patients who ultimately benefit from their labours. So I was fascinated to attend the biennial 11th International Scleroderma Workshop in Cambridge, Boston, Massachusetts earlier this year. This meeting of scientists and clinicians was established 20 years ago by a group of rheumatologists who were at the vanguard of research in scleroderma at the time, some of whom still attend. True to the original vision, it remains small and independent of industry support and around 80% of the content is basic science. Many of the presentations are given by world-renowned scientists

"This synergism between scientists and clinicians is improving the understanding of the disease processes underlying scleroderma and offers hope for innovative solutions."

Of course, these are not the only problems that can affect hand function in patients with scleroderma. Arthritis, joint contractures due to tightened skin and muscle weakness might all need addressing to reduce pain and improve functioning. In the patient version of this issue of "Scleroderma Connections", find information about Independent Living Centres in each state, for helpful advice for these problems.

Also in this issue, we have a report on the Australian Scleroderma Screening Programme workshop which was a wonderful opportunity for nurses, data managers and doctors to share ideas about how to improve the running of the programme. Thanks to Jill Byron and Dr Wendy Stevens for hosting us so graciously. As well as the usual update on the screening programme, a new feature in the newsletter is the "Get to Know Your Centre" section which profiles one of the

whose work has broader applications but offers new paradigms applicable to scleroderma. This synergism between scientists and clinicians is improving the understanding of the disease processes underlying scleroderma and offers hope for innovative solutions. The value of patient registries in this process is a recurring theme and highlights the importance of the ASIG database.

We had some wonderful feedback about the first issue of "Scleroderma Connections". If you have any comments or suggestions for future issues, we would be pleased to hear from you.

Happy reading!

Susanna

Susanna Proudman
ASIG Chair



contact.

RESEARCH QUERIES

Jill Byron, Project Manager
Ph: 03 9288 3986 Email: 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



WELCOME
Susanna Proudman

PROFILE
Monash Medical Centre

STUDY
Pulmonary Fibrosis

ASIG RESEARCH
FELLOW FOR 2011
Appointment

SCLERODERMA
AUSTRALIA
Support group

TIPS
Aids available from
Independent Living Centres



**Australian
Rheumatology
Association**

www.rheumatology.org.au

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SCLERODERMA CONNECTIONS

PATIENT NEWS

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profile.



Dr Joanne Sahhar



Kathleen Elford

Monash Medical Clinic

VICTORIA

Dr Joanne Sahhar is the rheumatologist co-ordinating the scleroderma screening program at Monash Medical Centre with assistance from her nurse, Kathleen Elford.

Dr Sahhar has a long interest in scleroderma. She set up the Victorian Database in 1999 with Dr Stevens (St Vincent's Hospital), which was the forerunner to the current ASIG database. Her particular interest is in lung disease/lung fibrosis.

The clinic is held on Wednesday mornings and it is a privatized bulk billing clinic which runs in the private consulting suites of the hospital with all visits, pathology and screening tests being bulk billed and screening tests generally performed on one day.

Kathleen works on Wednesday and Thursday in the Scleroderma unit and can be accessed on 9594 3566 on these days with a message service for other days. Referrals from patient's doctor should be sent to Kathleen on fax 9594 6512.

Kathleen has expertise in ulcer and wound management and is able to provide education and assistance with wound dressing and management. The centre currently has 99 patients enrolled in the screening program, most of whom return for annual review.

Dr Gene Ngian, a rheumatology fellow, assists Dr Sahhar with the review of patients in the clinic. Gene is also doing a PhD examining the prevalence of cardiovascular disease in Scleroderma, the role of arterial stiffness in predicting vascular disease and potential risk factors for cardiovascular disease in patients with Scleroderma.

study.

Pulmonary Fibrosis

Pulmonary fibrosis or interstitial lung disease (ILD) is a common complication of scleroderma. However the clinical course of ILD is considerably variable.

Whilst most patients have very mild and minimally progressive involvement there are a few patients in whom the lung disease is extensive and progressive and can lead to severe disability. Treatment with immunosuppression has been shown to be of some benefit in those with more severe and progressive disease. However the treatments that have been found to be of benefit have considerable risk of side effects and thus are only used in patients in whom there seems to be a high likelihood of progression of the lung disease. One of the major challenges in treating ILD in scleroderma is predicting which patients are going to progress and should thus have these therapies. A recent study from the UK of patients with scleroderma associated ILD referred to a specialist lung clinic found that the best predictor of progression of lung disease was the extent of involvement on a CAT scan of the lungs. They subsequently devised a simple scoring system for grading ILD according to the CAT scan.

We are proposing to test this system of scoring using the results in our ASIG database to see if it really can be used to predict patients more likely to have progression of their lung disease. We will also be using data already collected in the database to see if other factors such as disease duration or antibody subtype will provide helpful additional information in predicting those that are likely to progress and therefore should be treated for their ILD. To do this we will be trying to collect and copy any CAT scans of patients in the database who are known to have ILD and will then have them graded by a panel of specialist radiologists trained in this scoring system. We hope to commence the project later this year. Patients may be contacted by their centre to ask if they can bring in any of their previous CAT scans of the lungs so they can be copied and used in this particular project.

Further information on this study can be obtained from the ASIG Project Manager, Jill Byron.

Fellow Appointment

The ASIG was pleased to recently announce that the Scleroderma Research Fellowship for 2011 was awarded to Dr Vivek Thakker.

Vivek is currently completing his second year of advanced training at Liverpool Hospital in Sydney. He was involved with the project that won the 2010 ARA Best free paper (clinical) award for a presentation entitled "Rheumatologists practice Evidence Based medicine, an observational study" and the prize for the best case presentation at the 2010 ARA National Grand Rounds. We look forward to him joining the ASIG team and contributing to the research output.

support group.

Scleroderma Australia

Scleroderma Australia is the national association for people with scleroderma, their families and friends.

It was formed by joining together existing state organisations who shared a vision for elevating the cause of scleroderma patients in Australia - "together we are stronger." Scleroderma Australia is not-for-profit and funded by member states, individual and corporate donations.

Scleroderma Australia exists to:

- Promote scleroderma awareness on a National basis
- Disseminate information about scleroderma
- Fund and coordinate scleroderma research on a National basis
- Advocate for improved and ongoing support for scleroderma patients

Scleroderma Australia provides:

- Educational seminars and information for patients
- State-based support groups
- Support for scleroderma research
- Website with news and information
- Centralised message bank, 02 9990 5159 (Calls usually returned within 24 hours)
- Annual National awareness campaign

Scleroderma Australia has organisations in each State. We would welcome new members to join us and perhaps become part of the many Support Groups throughout Australia.

Further information and resources can be found on our website:

www.sclerodermaaustralia.com.au

Under "Highlights" you can view a video of a recent education day held at St. Vincent's Hospital, Melbourne, where eight experts gave talks on many aspects of this disease.

Robyn Sims, President

tips.

Aids available from Independent Living Centres

Independent Living Centres (ILCs) are a great resource for anyone experiencing difficulties with aspects of their day to day life caused by their illness. ILC's provide information on assistive technology, defined as "any device, system or design, whether acquired commercially or off the shelf, modified or customised, that allows an individual to perform a task that they would otherwise be unable to do, or increase the ease and safety with which a task can be performed".

Trained staff at ILCs including occupational therapists are able to provide impartial advice and information on options available. An example is the ring-pen as shown below.



If you are interested in finding out more about ILC's you can check the Australian website which gives information on centres located in each State.

www.ilcaustralia.org/home/search.asp