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*When you can't breathe...
nothing else matters*

MEDIA RELEASE

REGISTER FOR RARE LUNG DISEASES GATHERS MOMENTUM

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"Collection of data for The Australian Lung Foundation's Australasian Registry Network for Orphan Lung Diseases (ARNOLD) from July 1 2009 will put the spotlight on interstitial and orphan (rare) lung diseases – ***the forgotten diseases***", says Associate Professor Adam Jaffe, member of The Australian Lung Foundation's Pulmonary Interstitial Vascular Organisational Taskforce and Head of Respiratory Medicine at Sydney Children's Hospital.

"Interstitial and orphan lung diseases are uncommon and doctors and patients frequently have difficulty understanding what causes them and what the best treatments are", continued Associate Professor Jaffe.

"As a result, patients often experience inequity in service provision compared to those with more common lung diseases", he said.

Officially launched in November 2008, the Registry, developed in consultation with key opinion leaders in interstitial and orphan lung disease in Australasia and the Thoracic Society of Australia and New Zealand (TSANZ), is a ground-breaking initiative which will capture the incidence and prevalence of interstitial and orphan lung diseases in Australasia, raise the profile of these diseases, increase understanding of what causes them and encourage studies of new treatments.

Associate Professor Jaffe went on to say that a website for ARNOLD has been launched at www.arnold.org.au and includes information about the different lung conditions, an online Patient Forum and provides physicians with a simple email/web-based method for recording monthly incidence data on pre-determined lists of adult and paediatric orphan lung diseases.

The development of ARNOLD was welcomed by patient advocate, Mrs Miriam McLean who has pulmonary fibrosis, and is the consumer representative of The Australian Lung Foundation's Pulmonary Interstitial Vascular Organisational Taskforce.

"This will sweep rare lung diseases out from under the carpet and raise their profile. It is an important step for patients to know that there is now some interest in conditions that we have felt, for a long time, have been ignored. Hopefully, this will lead to more treatment options and better patient support", said Mrs McLean.

For further information, please contact Associate Professor Adam Jaffe on 02 9382 1477, or Ms Juliet Brown on 07 3251 3640

Mrs McLean runs a support group in Sydney for patients and carers affected by pulmonary fibrosis and interstitial lung disease and also provides telephone and online support to patients and carers around Australia.

Australasia does not have an accurate picture of the number of patients who suffer from orphan lung diseases, defined as diseases with a prevalence of less than 1 in 2000. Approximately 7000 rare lung diseases have been identified worldwide.

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