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MEDIA RELEASE

REGISTER FOR RARE LUNG DISEASES

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The Australian Lung Foundation will launch an Interstitial and Orphan Lung Disease Registry to capture the incidence and prevalence of rare, or 'orphan' lung diseases in Australasia on Interstitial & Orphan Lung Disease Day (November 24).

Developed in consultation with key opinion leaders in interstitial and orphan lung disease in Australia, the Australasian Registry Network for Orphan Lung Diseases (ARNOLD) aims to determine the number of patients affected by rare lung diseases, ensuring greater public and government awareness of their incidence and prevalence

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

Associate Professor Adam Jaffe from the Sydney Children's Hospital, is a driving force behind the Registry and is a member of The Australian Lung Foundation's Pulmonary Interstitial Vascular Organisational Taskforce. Associate Professor Jaffe had extensive involvement in the development of the British Paediatric Orphan Lung Disease register.

"As interstitial and orphan lung diseases are uncommon, doctors and patients find it difficult to understand exactly what causes them and what the best treatments are. Patients often experience inequity in service provision compared to patients with more common lung diseases. It is hoped that the Registry will raise the profile of the plight of these patients, increase our understanding of what causes these diseases and encourage studies of new treatments", said Associate Professor Jaffe.

The announcement was welcomed by pulmonary fibrosis patient, Mrs Miriam McLean, consumer representative of The Australian Lung Foundation's Pulmonary Interstitial Vascular Organisational Taskforce. Mrs McLean organises a support group in Sydney for patients and carers affected by pulmonary fibrosis and interstitial lung disease, and also provides telephone and online support.



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“This will sweep pulmonary fibrosis and other 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.

The Registry will provide an email/web-based method for recording monthly incidence data on pre-determined lists of paediatric and adult orphan lung diseases, as well as idiopathic pulmonary fibrosis.

Physicians treating patients with interstitial and orphan lung diseases will be asked to register their interest, with work on data collection to start in 2009. Internationally, the need for a registry of interstitial and orphan lung diseases has been recognised and steps have been taken to develop registries in Europe[1], [2], [3] and America.

Interstitial lung diseases are included in the rare lung disease category and are conditions which affect the lung tissue. In these conditions, scarring (fibrosis) of the air sacs (alveoli) results in the development of severe shortness of breath and the disease may affect the patient's quality of life. They include idiopathic pulmonary fibrosis, for which there is also no incidence and prevalence data available in Australasia.

Through the collection of data on patients with interstitial and orphan lung diseases, the aim of the Registry is to increase understanding of these diseases and enable contribution to international registries. It is hoped that these data will generate research, promote clinical knowledge of these diseases, and encourage the formation of patient support groups.

The development of ARNOLD builds on work conducted by the Australian Scleroderma Interest Group which has established screening centres across Australia for patients with scleroderma or mixed connective tissue disease.

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References

- [1] Wilson JW, du Bois RM, King TE, Jr. Challenges in pulmonary fibrosis: 8--The need for an international registry for idiopathic pulmonary fibrosis. *Thorax*. 2008 Mar;63(3):285-7.
- [2] Lavery A, Jaffe A, Cunningham S. Establishment of a web-based registry for rare (orphan) pediatric lung diseases in the United Kingdom: the BOLD registry. *Pediatr Pulmonol*. 2008 May;43(5):451-6.
- [3] French National Plan for Rare Diseases 2005 – 2008 20 November 2004.