

MEDIA RELEASE

NEW REGISTRY TO BE SET UP AT THE ALFRED HOSPITAL FOR PATIENTS DIAGNOSED WITH FIBROMUSCULAR DYSPLASIA (FMD)

December 6, 2014 and Docklands Library Meeting Room, was a gathering point to hear Dr. Scott Wilson, BMedSci (Hons) MBBS (Hons) PhD FRACP, Nephrologist and Physician in Dialysis from Alfred Health and the Baker IDI, speak about **Fibromuscular Dysplasia (FMD)** and his findings with FMD patients.

Prior to hearing Dr. Wilson's address, fellow FMD'er and retired nurse/teacher, Rhonda Favaloro, gave a short overview on the mechanisms that control our blood pressure.

One of the most exciting points of Dr. Wilson's presentation was to learn that a **New Registry** is being established which will be open to both renal and non-renal FMD patients.

"The Registry aims to collect timely diagnostic treatment and epidemiological data across a spectrum of renal diseases for the purposes of collaborative research and ongoing quality assurance", Dr. Wilson said. He then went on to advise:

The Victorian State Government has committed to the establishment of the "Registry of Kidney Disease" (ROKD) being coordinated through the Renal Health Clinical Network and geographically located at The Alfred Hospital.

The Alfred is the first site to provide commitment and data extractions although the ROKD has local leadership across the Royal Melbourne, Monash, St Vincent's, Western General and Austin Hospitals so far.

The initial phases of the ROKD are restricted to a small selection of renal diseases prior to planned rollout across the specialty; however, Dr Wilson was pleased to announce to the audience that Fibromuscular Dysplasia has been included as one of the core conditions for the Registry's inception.

One of the FMD patients present at the meeting, welcomed the news that this new Registry will also help to monitor and manage her condition. FMD had been diagnosed in her carotid arteries following a STROKE some years back. Since then, despite having no pre-existing factors other than undiagnosed high blood pressure, she has had coronary bypass grafts, a cardiac stent, diagnosis of renal FMD, and further transient ischemic attacks (TIA's).

This exciting news will bring Australia in line with other medical centres around the world who are researching Fibromuscular Dysplasia (FMD).



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