



Registry of Kidney Diseases

NEWSLETTER
1st Edition
February 2016

Welcome!

Introduction

Welcome to the first edition of the Registry of Kidney Disease (ROKD) newsletter.

Who are we?

ROKD is a clinical quality registry which collects data from patients with Chronic Kidney Disease (CKD) across a spectrum of renal specific diseases (RSDs) and some rare diseases affecting the kidney.

The primary aim of ROKD is to identify patients from early stages CKD, monitor their disease progression towards End-Stage Kidney Disease (ESKD) and the care provided to them.

What data are collecting?

We are collecting information on 7 RSDs. These are:

1. Primary focal segmental glomerulosclerosis
2. Membranous glomerulonephritis
3. Autosomal dominant polycystic kidney disease
4. Fibromuscular dysplasia
5. IgA nephropathy
6. Alport syndrome
7. Tuberous Sclerosis Complex

Current sites

ROKD is in its pilot stage and has commenced patient registration in 6 Victorian hospitals:

- Alfred Health
- Austin Health
- Monash Children's Hospital

- Monash Medical Centre
- Royal Melbourne Hospital
- Western Health

Plans are in process to commence ROKD at 11 more Victorian sites in 2016.

FAQs

Q1. I am interested in ROKD, how do I get my site added as a study site?

A1: Contact ROKD staff on the ROKD email and details on this process will be provided.

Q2. Will ROKD be expanding to include other states?

A2. ROKD is still in its pilot stage, there are plans for ROKD to be a national registry in the future.

This issue

Welcome! P.1

Who are we? P.1

What data do we collect? P.1

Current ROKD sites P.1

FAQs P.1

Registry staff

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For more information

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