Birmingham Children's Hospital NHS
NHS Foundation Trust

RaDaR

Overview of Rare Renal Diseases at a UK Paediatric Renal Centre through the National Registry of Rare Kidney Diseases (RaDaR)

M. Kokocinska, L. Kerecuk, D. Milford, S. Hulton, M. Muorah Birmingham Children's Hospital; M.Dillon, UK Renal Registry

Background

The National Registry of Rare Kidney Diseases (RaDaR) is a UK Renal Association initiative designed to gather information from patients with rare kidney diseases. Recruitment began in 2010 and now covers over 30 conditions. There are over 7,000 recruits from 70 renal units.

This poster describes the range of conditions and patient numbers recruited to RaDaR from Birmingham Children's Hospital (BCH), a national tertiary renal referral hospital and the leading paediatric recruiter in the UK.

Objectives

BCH use RaDaR to identify eligible patients for family information days and to tailor clinical interventions and access genetic testing services. In the future it is intended to be used to design clinical trials to improve diagnosis and treatment.

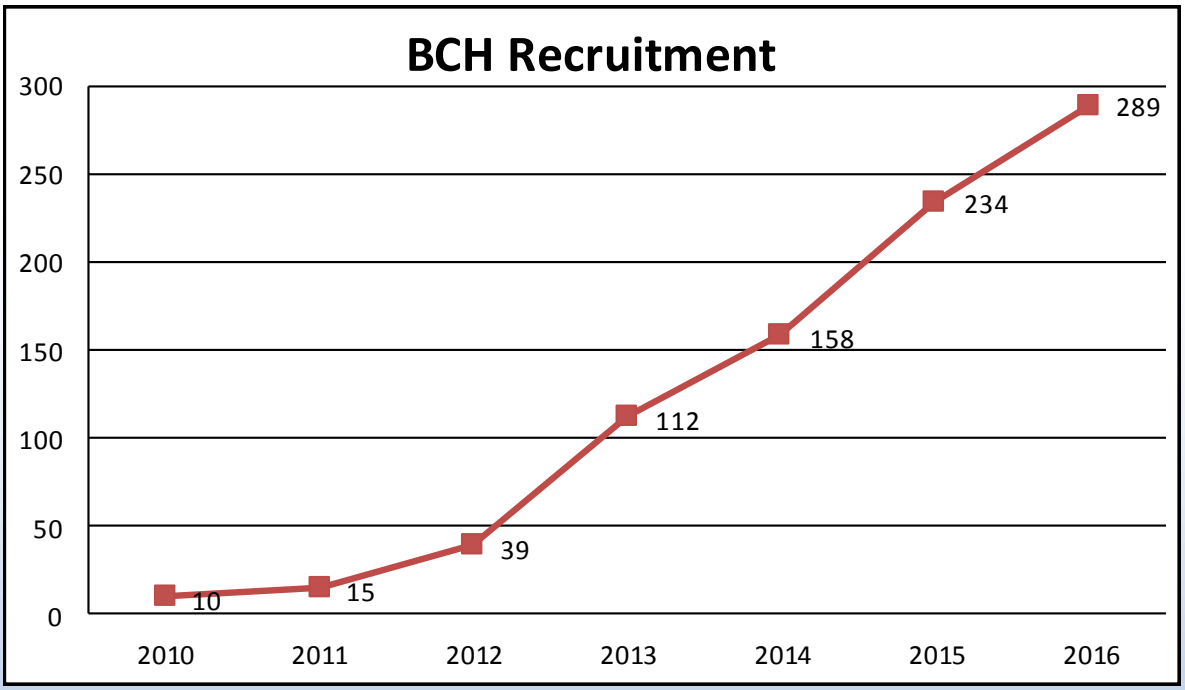
Methods

The RaDaR dataset is defined by the UK Renal Registry in association with over 20 Rare Disease Groups, made up of experts in each eligible condition. Data fields include demographics, blood and urine results, medications, transplant and dialysis history, genetics and co-morbidities. Data is entered retrospectively from the patient's medical records following consent.

Results

289 patients have been consented at BCH to date. The age range is from birth to 16 years with mean of 4.9 years. The male to female ratio is 55%:45%.

The most common condition is Idiopathic Nephrotic Syndrome (n=119; 39%), followed by Alport Syndrome (n=32; 12%), ARPKD (n=24; 9%), Hyperoxaluria (n=23; 9%) and Stec HUS (n=21; 8%).



Conclusion

RaDaR provides important epidemiology data which is shared amongst the renal team to facilitate further research into rare kidney diseases, develop evidence-based clinical guidelines and improve the quality of care for these patients.

RaDaR is supported by:

BRITISH KIDNEY Patient ASSOCIATION improving life for kidney patients
Kidney Research UK Funding research to save lives
NHS England
pkd charity Polycystic Kidney Disease
Renal Association UK Renal Registry

If you have any questions in regards to this review or the results please contact: Maria.Kokocinska@bch.nhs.uk