

RaDaR Rare Disease Group Annual Report

April 2015 – March 2016

Rare Disease Group	ARPKD
Lead Clinician	Larissa Kerecuk
Summary of RDG meetings	RDG Meeting December 2015
Summary of patient events	Patient Information Day in Leeds July 2015
Grant applications submitted	PKD Charity grant for RaDaR data fields SPARKS funding for patient event
Grants awarded	As above
Publications and presentations	Abstracts submitted in March 2016 for IPNA. Rationale, design and objectives of ARegPKD, a European ARPKD registry study, Ebner, E. et al, BMC Nephrol. 2015; 16: 22
Highlights	5 th annual patient support day Organising international classification Potential biomarker study with Edinburgh University
Problems	Resources for research