

## Rare Diseases Operational Management Board (OMB)

### RDG End of Year Report 2013

Dear RDG Coordinator,

Please file a report to the OMB for your activity in the calendar year 2013, and return it to Chrissie Jacobs at UKRR no later than 15<sup>th</sup> January 2014. Ongoing recognition of the RDG by the Renal Association is dependent on receipt of a report.

This report is deliberately minimal and should not take long to complete, not least because some of the information is obtainable centrally by the OMB. Emphasis is placed on the early benefits for patients which focuses on patient support meetings and patient engagement within the RDG.

Please fill out the table below and return the entire word document with any supplements that you wish to be filed, specifically minutes of RDG or patient information meetings.

Name of RDG	<b>ARPKD Rare Disease Working Group</b>
Name of Coordinator	Dr Larissa Kerecuk
Name of Administrator Email address Telephone number	Melanie Dillon Birmingham Children's Hospital
Name of person/person's cleared to work with patient identification Email address Telephone number	Melanie Dillon
RDG meetings: Summary <i>(append written minutes if that is easier)</i>	Minutes of working group meetings from July and December 2013 attached.
Patient Information meetings :Summary <i>(append written minutes if that is easier)</i>	Second ARPKD Patient Information Day held 6 <sup>th</sup> July 2013 in Birmingham. Schedule and feedback report attached.
Grant applications submitted	None this year
Grants awarded	None this year
Publications and presentations	An international consensus meeting took place in Washington DC in May 2013 to draw up best practice guidelines for ARPKD, in preparation for Publication in J Pediatrics.
Highlights (free text)	The second UK ARPKD Patient Information Day was held on the 6 <sup>th</sup> April 2013 in Birmingham and attended by over 80 participants.

	All but one ARPKD BCH patients have now been approached about RaDaR. 14 out of 16 are consented and on the Registry.
Problems (free text)	Granular data fields still not available for RaDaR, limiting data entry