

RaDaR Rare Disease Group Annual Report

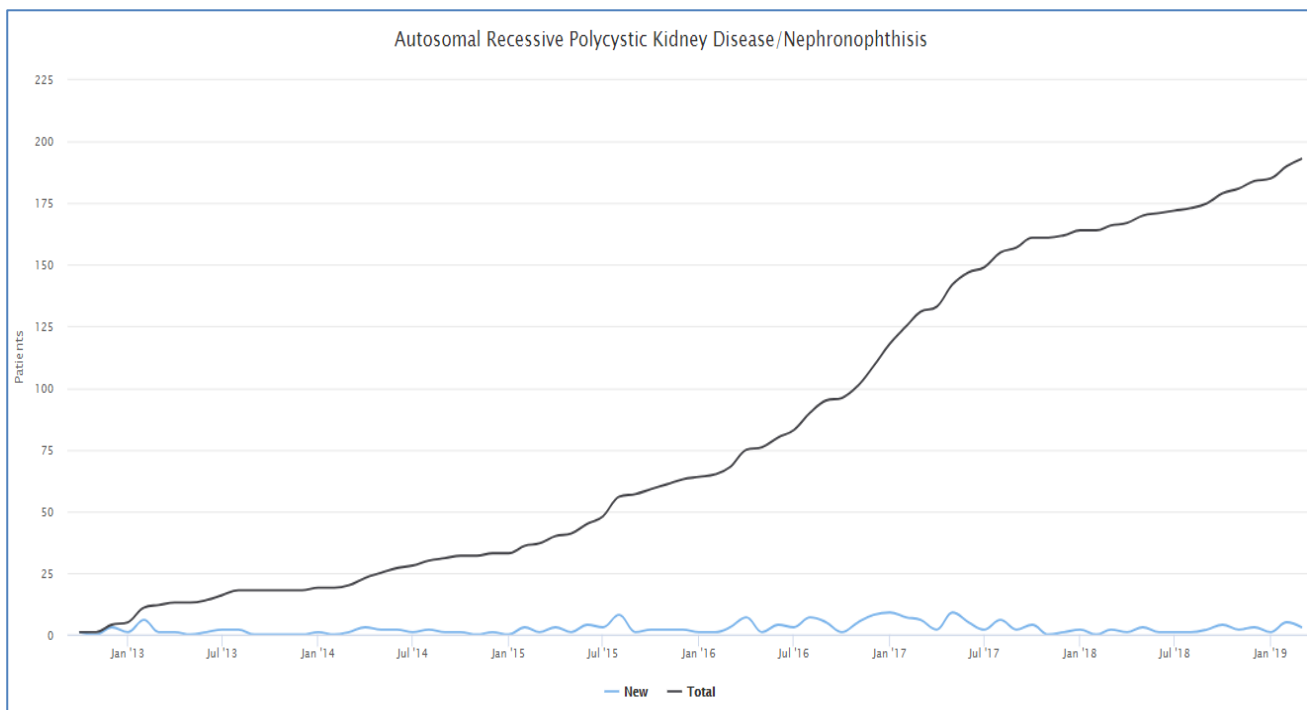
April 2018 – March 2019

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| <p>Rare Disease Group</p> | <p>ARPKD/NPHP</p> |
| <p>Lead Clinician</p> | <p>ARPKD: Larissa Kerecuk Interim: Pat Wilson NPHP: Shalabh Srivastava</p> |
| <p>Summary of RDG Activity (Meetings, patient events)</p> | <p>ARPKD</p> <p>Business meeting 27/07/2018</p> <p>Patient day Newcastle 02/2019</p> <p>Addition of NPHP to RDG</p> <p>Update of ARPKD/NPHP- RDG website content</p> <p>NPHP</p> <p>This is the latest addition to RaDaR and the first business meeting is planned for the 10th of May 2019.</p> <p>We are in the process of spreading awareness about this condition and a special session is planned on the first day of the UK Kidney Week 2019.</p> |

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| <p>Grants awarded that use RaDaR infrastructure or data</p> <p>(Please do not include other grants awarded to RDG members)</p> | <p>ARPKD</p> <p>Funder: PKD Charity</p> <p>Title of project: ARPKD RaDaR Award: specialist nurse to increase recruitment and enrich data . Bioresource Bank</p> <p>Principal Investigator(s): Prof P. Wilson Amount: £30,000</p> <p>PhD studentship to study ARPKD Mechanisms: PKD charity, T. Richards, University Wolverhampton. Supervisor P. Goggolidou</p> <p>Funder: CRN NIHR WM and PKD Charity</p> <p>Title of project: Stars Together Rare Disease Registry</p> <p>Principal Investigator(s): Larissa Kerecuk (CI)</p> <p>Amount: £20000</p> <p>NPHP None</p> |
| <p>Conference posters/presentations using and acknowledging RaDaR data</p> | <p>ARPKD</p> <p>PKDOCS presentation :Use of RaDaR database. T Harris</p> <p>Renal Association 2018</p> <p>NPHP: None</p> |
| <p>Publications using and acknowledging RaDaR data</p> <p>(Please do not include other publications by RDG members)</p> | <p>ARPKD</p> <p>Guidelines for prenatal cystic kidney disease</p> <p>Contribution to Global AregPKD</p> <p>RA/BAPN guideleines: Care of children with or at risk of PKD</p> <p>NPHP</p> <p>None</p> |

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| <p>Number of commercial partners using RaDaR data to inform study design or recruitment sites</p> | <p>ARPKD</p> <p>OTSUKA ADPKD Trial</p> <p>Stars Together Registry</p> <p>NPHP</p> <p>None</p> |
| <p>Recruits as of 1st April 2018</p> | <p>167 (ARPKD only)</p> |
| <p>Recruits as of 31st March 2019</p> | <p>NPHP opened to recruitment December 2018. Figures are combined with ARPKD recruits</p> <p>196</p> |
| <p>New recruits</p> | <p>29</p> |

Recruitment Overview Graph



Patients by site

| Hospital | Patients |
|-------------------------|----------|
| Birmingham Childrens | 34 |
| Stevenage-Lister | 18 |
| Newcastle-Freeman | 12 |
| London - Guy's | 12 |
| Carshalton-St Helier | 12 |
| GOSH | 10 |
| Nottingham-Children's | 10 |
| London-Royal Free | 9 |
| Manchester Children's | 8 |
| Leeds - Children's | 8 |
| Hull | 6 |
| Nottingham City | 5 |
| London - King's | 5 |
| Cardiff - UHW | 4 |
| Liverpool Royal | 4 |
| Glasgow - Children's | 3 |
| Kent and Cant | 3 |
| Wolverhampton-NC | 3 |
| Bristol - Southmead | 3 |
| Bristol-Children's | 3 |
| Torbay | 2 |
| Inverness | 2 |
| Aintree | 2 |
| Edinburgh Royal | 2 |
| Chelmsford - Broomfield | 2 |
| Oxford-Churchill | 2 |
| Shrewsbury | 2 |
| Birmingham-Heartlands | 2 |

| Hospital | Patients |
|-----------------------|-----------------|
| Plymouth | 2 |
| Sheffield | 2 |
| Gloucester | 2 |
| Leicester | 2 |
| Alder Hey | 2 |
| Arrowe Park | 2 |
| Glasgow - QEUH | 1 |
| Kilmarnock-Crosshouse | 1 |
| Birmingham-QEH | 1 |
| Dudley - R Hall | 1 |
| Manchester RI | 1 |
| Norfolk and N | 1 |
| Carlisle | 1 |
| Stoke | 1 |
| London - St George's | 1 |
| Brighton | 1 |
| Cambridge | 1 |
| Colchester | 1 |
| Basildon | 1 |
| Southampton-Childrens | 1 |