**RaDaR Rare Disease Group Annual Report**

**April 2016 – March 2017**

<table>
<thead>
<tr>
<th>Rare Disease Group</th>
<th>Idiopathic Nephrotic Syndrome/NephroS</th>
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<td>Lead Clinician</td>
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<td><strong>Summary of RDG meetings</strong></td>
<td>Single face to face meeting on 05/05/2017 to discuss MRC stratified medicine application</td>
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<td><strong>Summary of patient events</strong></td>
<td>Patient Information Day held at the University of Bristol on 29th March 2017.</td>
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| **Grant applications submitted** | MRC stratified medicine – shortlisted for final stage  
MRC capital biobanking bid – shortlisted for final stage |
| **Grants awarded** | • MRC global challenges award that will enable the RaDaR/NephroS study to open in 4 new International sites in India (two sites), South Africa and Egypt (£600k)  
• Kids Kidney Research (KKR) award for Personalised immunomonitoring in nephrotic syndrome - towards a molecular re-classification of disease. (£100k)  
• NURTuRE – the National UK Renal Translational Research Enterprise. An industry funded (£2.7M) collaboration with academia and clinicians to set up a national network of renal research nurses in the UK. Pilot cohorts are NS and CKD |
Publications


Presentations
Agnieszka Bierzynska will be presenting during the Young Investigators Session at UK Kidney week: The title of her talk will be “Identification of novel NUP93 mutations in SRNS and evidence for a functional role for this protein in the regulation of podocyte biology”.
### Highlights

- Huge surge in recruitment – with 143 children and 303 adults recruited this year to NephroS.
- NURTuRE project – due for official launch at UKKW June 2017.
- Global Challenges project funded by MRC. This will include development of ‘International RaDaR’ website.

### Problems

- Some centres unable to copy clinic letters – it would be ideal to have an upload facility for pdf documents
- Problem with Patient view feed in two INS patients.