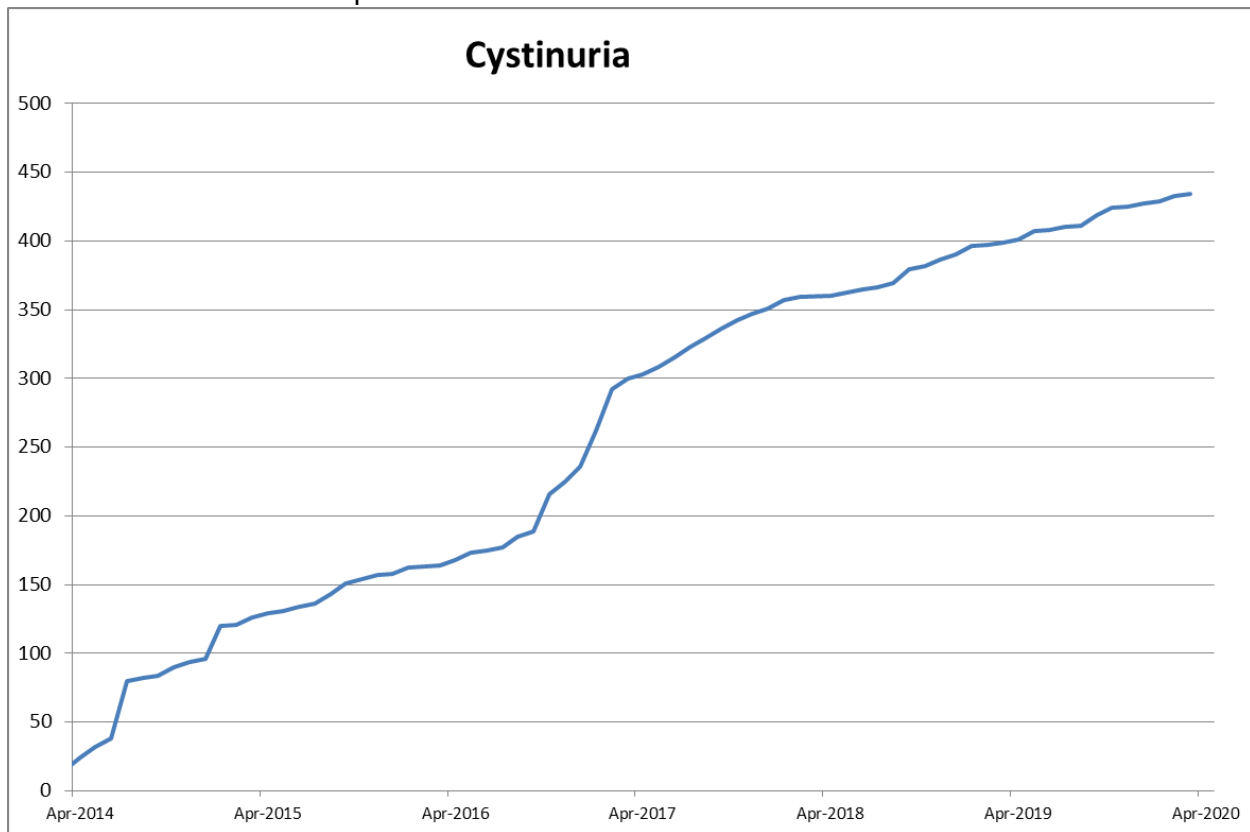


RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

| | |
|---|---|
| Rare Disease Group | Cystinuria |
| Lead Clinician | Kay Thomas; Richard Coward |
| Summary of RDG Activity (Meetings, patient events) | March 30 th 2019 – Patient Day at Guy’s Hospital |
| Grants awarded that use RaDaR infrastructure or data (Please do not include other grants awarded to RDG members) | None Reported |
| Conference posters/presentations using and acknowledging RaDaR data | None Reported |
| Publications using and acknowledging RaDaR data (Please do not include other publications by RDG members) | None Reported |
| Number of commercial partners using RaDaR data to inform study design or recruitment sites | None Reported |
| Recruits as of 1st April 2019 | 399 |
| Recruits as of 31st March 2020 | 434 |
| New recruits | 35 |

Recruitment Overview Graph



Recruits by site

| Hospital | Patients |
|--|----------|
| London - Guy's and St. Thomas' Hospital | 163 |
| Newcastle upon Tyne - Freeman & Victoria Hospitals | 37 |
| London - Royal Free Hospital | 36 |
| Cambridge Kidney Unit | 28 |
| Birmingham - Queen Elizabeth Hospital | 17 |
| Bristol - Southmead Hospital | 14 |
| Truro - Royal Cornwall Hospital | 9 |
| Sunderland Royal Hospital | 8 |
| Bradford Renal Unit | 8 |
| Manchester Childrens Hospital | 8 |
| Plymouth - Derriford Hospital | 8 |
| Southampton Childrens Hospital | 7 |
| Birmingham Childrens Hospital | 7 |
| Salford Royal Manchester | 6 |
| Huddersfield Royal Infirmary | 6 |
| Stoke -Royal Stoke University Hospital | 5 |
| Sheffield - Northern General Hospital | 5 |
| Nottingham - QMC - Children's Kidney Unit | 4 |
| Cardiff - UHW (Adult and Paediatrics) | 4 |
| Middlesbrough - James Cook | 3 |

| | |
|--|---|
| Leeds - Childrens Hospital | 3 |
| Basildon Hospital | 3 |
| Glasgow - Queen Elizabeth University Hospital | 2 |
| London - Barts Health | 2 |
| Bristol Royal Hospital for Children | 2 |
| Manchester Royal Infirmary | 2 |
| Brighton - Sussex Kidney Unit | 2 |
| Derby - Royal Derby Hospital | 2 |
| Leicester | 2 |
| Hull | 2 |
| Edinburgh Royal Infirmary | 2 |
| Southend | 2 |
| Dundee Ninewells | 2 |
| Inverness - Raigmore Hospital | 2 |
| Newry - Daisy Hill Hospital | 2 |
| Oxford - Churchill | 2 |
| Exeter - Royal Devon and Exeter Hospital | 2 |
| Kent and Canterbury Hospital | 2 |
| Darlington | 1 |
| Chelmsford - Broomfield Hospital | 1 |
| Airedale General Hospital | 1 |
| York | 1 |
| Liverpool Royal UHT | 1 |
| Gloucester - Gloucestershire Royal Hospital | 1 |
| London - Great Ormond Street Hospital for Children | 1 |
| Preston | 1 |
| Carshalton - St Helier Renal Unit | 1 |
| Aberdeen Royal Infirmary | 1 |
| Colchester General Hospital | 1 |
| Swansea - Morriston Hospital | 1 |
| Norfolk and Norwich University Hospital | 1 |