Latest Developments in RaDaR and RareRenal.org Rare Disease Registry

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RenalRadar.org

RareRenal.org
Information on rare kidney diseases

THE RENAL ASSOCIATION
founded 1950

Background

- The **National Registry of Rare Kidney Diseases (RaDaR)** recruited its first patient in January 2010.

Recruitment has exceeded the target set in 2009 of 500 patients. NIHR are content to revise the target upwards. Numbers of recruits over all eligible conditions stand at 1311 (at 31/08/2014).

Study Type	Observational
Design Type	Cohort study
Disease(s)	All Diseases
Current Status	Open
Closure Date	1/1/2015
Global Sample Size	500
Global Recruitment to Date	235%

Source: UK Clinical Research Network : Portfolio Database Accessed 06/08/2014

Cohort Building

- Particular focus at present is to recruit patients with:
  - Membranous Nephropathy
  - Cystinosis
- However, the ultimate aim is to approach and hopefully recruit all eligible patients in all UK renal units.

Recruitment Levels

- One of the original groups, SRNS has developed a useful cohort of 328* patients the basis for several research publications.
- The other original group MPGN has 187* patients and produced a range of publications too.
- Adding to the cohort of Membranous Nephropathy alongside an existing MRC funded project has brought RaDaR patient numbers up to 127* for this condition.

Recruitment Levels

- Alport syndrome, where most of the patients are adult also has the potential to generate a sizable cohort of 66 patients in the existing system. The number of Alport patients in RaDaR currently stands at 66*.
- Vasculitis patient numbers are in excess of 250*.
- Cystinuria patients recruited stand at 81*, which is most encouraging since the diagnosis was only added to RaDaR in June 2013.

*All recruitment figures as at 31/08/2014

Link with Patient View (currently)

- If a patient entered into RaDaR is already in PV, their data will be pulled across automatically with no manual data entry required.
- Non-PV centres can still enter patients into RaDaR but manual data entry is required.
- Patients view their data via PV.
- RaDaR consent covers PV but not vice versa.

Current Recruitment

- Alport Syndrome
- Atypical Haemolytic Uraemic Syndrome (aHUS)
- Autosomal Recessive Polycystic Kidney Disease (ARPKD)
- Bartters Syndrome
- Dense Deposit Disease
- Epilepsy, Ataxia, Sensorineural deafness, Tubulopathy Syndrome (EAST)
- Cystinosis
- Gitelman Syndrome
- Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)
- Hyperuricaemic Nephropathy
- Liddle Syndromes
- Membranous Nephropathy
- Membranoproliferative Glomerulonephritis (MPGN)
- Medullary Cystic Kidney Disease
- Primary Hyperoxaluria
- Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)
- Steroid Resistant Nephrotic Syndrome (SRNS)
- Vasculitis
- Pregnancy and CKD
- Cystinuria
- Dent Disease
- Lowe Syndrome
- Pregnancy in Chronic Kidney Disease

Future Recruitment

Recruitment is about to open for:

Adenine Phosphoribosyltransferase Deficiency (APRTd)

and

Pure Red Cell Aplasia

Engaging All Sites

- The project employed a Project Facilitator who has visited 46 of the 70 + major sites. The Operations Manager has visited 2 sites, attended the South West Peninsula Researchers' meeting and The Scottish Renal Association Conference. (The Project Facilitator has resigned and the Operations Manager will undertake the remainder of the visits).
- The visits are intended to engage sites and we have noted a direct correlation between the sites visited the level of engagement.
- The visits are supported by support calls to and from the Operations and Informatics Managers.

Funding Database Development

Despite the development issues, RADAR is considered a success and a registry that the renal community and Renal Association would wish to see continue.

Financial sustainability could be achieved by:

1. capitation fees (preferred model)
2. annual subscription per unit
3. securing additional grant or other, e.g.industry funding
4. charge to researchers

Future Development

- The UKRR is developing a Data Warehouse which RaDaR will form part of. Data will flow into the warehouse from trusts and will be fed into the UKRR and RaDaR databases.

RareRenal.Org

The site was re-launched in June 2013. The amount of traffic on RareRenal.org demonstrates the importance of this resource to patients (as at 06/10/2014, more than 42,700 visits). Each RDG has an email address which, though named as if going to that RDG are directed to the RaDaR Operations Manager who redirects them as appropriate and maintains the audit trail. This facility has proved useful to patients and clinicians and has attracted interest from overseas. Although RareRenal.org emphasises that it cannot give advice to patients about their particular case, it is possible to give general advice and information. This communication route does allow clinicians to ask for advice about individual cases.

Contacts

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