RaDaR
Rare Disease Registry

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Background

- The National Registry of Rare Kidney Diseases (RaDaR) is a Renal Association initiative designed to pull together information from patients who have certain rare kidney diseases.

- This will give a much better understanding of how these illnesses affect people. It will also speed up research.

- RaDaR is managed by a series of Rare Disease Groups consisting of experts in each condition.

History

- RaDaR began in 2009, recruiting paediatric patients with Steroid Resistant Nephrotic Syndrome(SRNS) and Membranoproliferative Glomerulonephritis (MPGN)

- In 2012 it expanded to other conditions in paediatric centres and then to adult centres in Autumn 2013.

- RaDaR now has UK-wide ethics approval for both adult and paediatric recruits for 25 conditions.

Current Status of RaDaR

- There are currently:
  - 2,048 UK patients in RaDaR including:
    - 417 with Nephrotic Syndrome
      - 98 adults
      - 319 children

Link with Patient View

- RaDaR draws information from Patient View, an online system which records renal patient's results, medications and clinic letters.

- Recruited patients are given access to Patient View to see their data online.

- The majority of renal units in the UK use Patient View. Those that don't can still take part in RaDaR but have to enter the patient's data manually.

Data Collection

- RaDaR collects two types of data

  - Demographic - name, address, date of birth etc. This is to help your hospital identify your records. It does not get passed to the research team.

  - Medical - height, weight, blood pressure, blood and urine results, medications, etc. Updated every six months and visible to the research team as an anonymous record.

NephroS

- The National Study of **Nephro**tic **S**yndrome (previously called the SRNS study) is open to all patients with Nephrotic Syndrome - Steroid Resistant and Steroid Sensitive.

- Over 300 paediatric patients have been recruited to date, from 18 renal units in the UK.

- The study is now open in adult renal units as well.

NephroS

- Uses data collected as part of RaDaR
- Collects blood samples at:
  - Time of consent
  - At relapse and remission
  - Before and after kidney transplantation (if applicable)
- Plasma exchange bags are also collected if Nephrotic Syndrome returns after transplantation

NephroS

- Samples are sent to the Bristol research group for DNA sequencing and lab analysis. DNA results are reported back to your consultant to discuss with you.

- Lab data is used alongside RaDaR data to:
- Identify causes of Nephrotic Syndrome
- Identify common disease patterns.

- The ultimate aim is to develop:
  - Predictive tests to determine disease course
  - New drugs to treat Nephrotic Syndrome

Information Security

- Data is encrypted and password protected.

- Participants provided with a secure log-in to access and check their own information via Patient View.

- Identifiable data only available to patient's clinician and unit administrator.

- Members of the Rare Disease Groups will only see anonymised data - numbers rather than names.

To take part…

- If your child is treated at BCH:
- Collect an information sheet
- Sign the RaDaR consent form
- Hand back to me
  - NephroS consent will be taken at your next clinic visit

- If you or your child are currently treated elsewhere:
  - Collect an information sheet
  - Take to your doctor at your next appointment
  - Ask them to register you

RareRenal.org

- Patient information on rare kidney diseases, including Steroid Sensitive and Steroid Resistant Nephrotic Syndromes

- Contains links to support groups and reports of patient information days

- Written by experts in each condition and managed by the Renal Association

Contact Details

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