VESICOURETERIC REFLUX IN THE UK – ESTABLISHING A DNA COLLECTION FROM AFFECTED FAMILIES – FIRST YEAR REPORT

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PROBLEM: Primary vesicoureteric reflux (VUR) occurs in 1% of young children and first-degree relatives have a X 20-50 increased risk versus the general population. Associated reflux nephropathy causes 10% of end-stage renal failure in the UK.
PURPOSE: The genetic bases are unclear but it was estimated that 300 affected sibling-pairs and their parents would be sufficient to map major genetic loci. Here we describe the setting-up of a UK-wide research network aimed at making this collection.
DESIGN: Funding for the UK VUR DNA Bank had already been provided by the Wellcome Trust Functional Genomics group and salaries were available for two research assistants for three years. Our aims in Year One were to: establish a network of contacts in major UK Nephrology Centres, obtain UK-wide and local ethical approvals, obtain honorary contracts at all centres, identify and collect blood samples from affected families, design and set-up a clinical database, publicise the DNA Bank, hold initial meetings with a steering group who would oversee the use of the DNA Bank.
FINDINGS/ACHIEVEMENTS: Successfully established a network of contacts primarily through the 13 major UK Paediatric Nephrology centres and through selected Adult Nephrology and General Paediatric centres, obtained all MREC ethical approval and most local approvals, obtained honorary contracts in all centres, identified 99 families, contacted 62, had replies from 57 and blood samples have been taken from 41, developed a project specific electronic database where details of disease diagnosis, progression and treatment are stored, set-up a website (www.vur.org.uk) to inform potential investigators and families about vur and the existence and future use of the DNA Bank, met three times with a steering group (The National Kidney Research Fund DNA Development Group) who act as independent assessors of requests to access the resource once the project is complete. They are responsible for the promotion of the study.
CONCLUSION: Based on this first year progress report, our project to collect 300 families in three years is on-course and a firm multidisciplinary infrastructure has been established.
RELEVANCE: This project will establish a DNA Bank used for genetic analysis. The setting up of a VUR DNA Bank will assist in the exploration of the genetic basis of VUR, which may lead to a simple genetic test for identifying VUR.
It may also increase our understanding of urinary tract development.