

# Surveillance of End-stage Renal Disease (Stage 5 Chronic Kidney Disease) in early infancy.

**Start date.** May 2011

**Outline of Study.** Improvements in neonatal survival and advances in Renal Replacement Therapy have resulted in higher numbers of infants presenting with End-Stage Renal Disease (ESRD) in the first 6 months of life, for whom a decision has to be made to dialyse or treat palliatively. There have been anecdotal reports of increasing prevalence of ESRD in early infancy. The European Renal Association (ERA-EDTA) has reported that the incidence of Renal Replacement Therapy in the 0-4 year-old age group rose by over 100% from 2.4 per million of age related population (pmarp) in 1980-1984 to 5.5 pmarp in 1995-2000 but there is a paucity of population based data on the prevalence, morbidities or outcome of ESRD in early infancy. Controversy continues as to how best care for these infants with reports of poor outcome and significant morbidity. The provision of long term dialysis for young infants with ESRD presents a major public health issue. Management is complicated by complex clinical, ethical and health-care resource issues. The delivery of palliative care is also ethically and clinically challenging, with the provision of specialist health care from multiple disciplines needed to support the infant and family. This study will provide data on all infants in the UK and Ireland who reach ESRD in the first 6 months of life. The high ascertainment rates delivered by a BPSU study will provide accurate information on the natural history of ESRD in this population for the first time, helping to inform Health care policy and Health teams responsible for planning Nephrology services.

BPSU surveillance will be undertaken initially for 13 months, commencing in May 2011.

**Case definition.** Any infant from age 4 weeks to 6 months with presumed ESRD (CKD5) who has a serum Creatinine of equal to, or greater than 120 micromols/l.

ESRD (CKD5) is defined as either a Glomerular Filtration rate (GFR) of less than 15 mL/min/1.73 m<sup>2</sup>, which is accompanied in most cases by signs and symptoms of uraemia, or a need for initiation of kidney replacement therapy (dialysis or transplantation) for treatment for complications of decreased GFR, which would otherwise result in an increased risk of mortality and morbidity.

A serum creatinine of equal to, or greater than 120 micromols/l will give an estimated GFR of less than 15 mL/min/1.73 m<sup>2</sup> for infants in this population.

**Reporting instructions.** Please report any new cases you have seen in the last month which meet the surveillance definition. Please report to the BPSU even if you believe the case may have been reported from elsewhere.

**Website:** <http://www.bpsu.inopsu.com/studies/current.htm>

**Funding.** Northern Ireland Childrens' Renal Charity.

**Ethical approval.** This study has been approved by the Northern Ireland REC (Ref: 10/NIR03/32 )

**Further information.** If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact

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