**Use of Tolvaptan in a high risk ADPKD clinic: first 22 patient months**

**Background:** Tolvaptan was licensed to slow the progression of ‘high risk’ Autosomal Dominant Polycystic Kidney Disease (ADPKD) in late 2015. We set up a dedicated service to introduce and monitor prescribing in March 2016.

**Methods**: After analysing likely numbers and burden we established a one-stop multidisciplinary specialist ‘high risk ADPKD’ clinic. Patients thought to be eligible are sent advance information, counselled, and if they agree, issued with the drug immediately. Our algorithm and clinical protocol can be seen at **bit.ly/pkdedren**. For this review we established the clinical progress of all who had potentially been on treatment for at least 6 months; those who first attended the clinic before July 2017.

**Results:** Of 62 patients seen, 58 (94%) accepted treatment, some after deferring for some weeks or months. The CKD stage of patients was 12% stage 1, 31% stage 2 and stage 57% 3. 38 had been on treatment for 6-22 months, median 15 months. All patients report initial polyuria and thirst, usually dramatic. Overall, 18/58 discontinued the drug at a median of 3 months. Of those with at least 1 year of follow-up, 12 month ‘treatment survival’ was 60%. One patient discontinued tolvaptan after 12 months. We have observed informally that our ability to predict who will cope with the drug is poor. At 18 month reviews, patients appear adjusted to their ‘new normal’. Most patients (72%) achieved the maximum dose (90/30mg), usually over 4-6 weeks. One patient experienced abnormal LFTs necessitating permanent cessation of the drug at 6 weeks. No other major side effects have occurred. No overt AKI was identified.

**Conclusion:** Tolvaptan has been tolerated beyond 12 months by 60% of patients commencing the drug; 71% of those tolerate the drug for the first two months. An additional 11 patients are receiving tolvaptan in research studies, so we are treating 51 of 250 patients (20%) known to us with pre-renal replacement therapy ADPKD, and 49 are awaiting further investigation for eligibility. Approximately 9 patients with ADPKD start dialysis each year from our regional population of approximately 1 million (or 180 over the next 20 years; approximately the maximum duration that current guidelines aim to include). Therefore we are treating approximately 28% of the population who could benefit in the next 20 years.