

**USUAL TREATMENT PHASE**  
**SUMMARY: INFORMATION SHEET FOR**  
**PARENTS & GUARDIANS**

Version 4.0

**Infant **K**idney **D**ialysis and Filtration  
The **I-KID** Study**

**Invitation**

**We are doing a study to find out which dialysis method(s) gives the best support for very small babies. We would like to invite your baby to take part.**

Your baby will receive dialysis and the best possible care whether they are part of this study or not.

**To help you decide, this information sheet will give you some key information about the I-KID study. Please ask us if there is anything that is not clear or if you have any questions. We have also given you a more detailed information sheet to read now or at another time.**

**What is the I-KID Study?**

- The doctors and nurses have decided that your baby needs dialysis.
- There are several existing methods of dialysis used in hospitals for very small babies. These have been adapted from those designed for use with adults and older children.
- There is a new NIDUS dialysis machine which has been developed in Newcastle upon Tyne. It is specially designed for babies who weigh less than 8 kg and is being used at certain times in hospitals taking part in this study.
- This hospital will be getting the NIDUS in the near future, but it is not available to us just yet. At the moment we are looking at babies who are being treated using the existing dialysis methods.
- At the moment there is not enough information to tell us which method of dialysis gives the best support to very small babies. Taking part in this study will help us get this information so we can compare how well the different dialysis methods work and help babies in the future.

6 hospitals in the UK have agreed to take part in the I-KID study and collect information on very small babies who are on dialysis. There are **no extra hospital visits** needed and there are **no extra blood tests**.

As part of the study we will:

- Weigh the dialysis fluid bags for the first 2 days that your baby is on dialysis.
- Do some chemistry tests on the waste fluid that would normally be thrown away.
- Collect information about your baby whilst they are on dialysis. Most of the information we need is already collected by the hospital, but we will also collect the weight of the fluid bags and results of chemistry tests on the waste fluid.

#### **Parent/Guardian Questionnaire (optional)**

We will ask if you would be happy to answer a simple questionnaire. We want to know about your experience of having a baby on dialysis and how you found taking part in this study.

Your baby can still take part in this study even if you do not want to answer these questions.

#### **Does my baby have to take part?**

No, it is up to you to decide if you want your baby to take part in this study. You can change your mind and withdraw your baby from the study at any time.

If you say no, the type of dialysis that is best for your baby will be decided by your baby's treating clinician. Your baby will still receive dialysis and it will not affect their standard of care. Any information collected so far will not be used for this study..

If you agree for your baby to take part, we will ask you to sign a consent form.

#### **What happens next?**

A member of the team will come back to speak with you shortly. Please let them know if you would like to consent for your baby to take part in this study, or if you have any more questions. They will go through this information sheet with you before you make your final decision.

*If you want to discuss this sooner or if you do not want any further information or if you definitely do not want your baby to take part in this study, please let the team looking after your baby know.*