Cardiff Study Centre

NEWSLETTER

www.dutystudy.org.uk

Issue 6 May 2011

Welcome to the Sixth Edition of the Cardiff DUTY Study Newsletter!

We hope you enjoyed the Easter break and the fantastic addition of that extra public bank holiday - thanks to Wills & Kate for that! There's important information for recruiters to take note of this month; so please pay special attention to that. We are delighted to present in this month's issue an interview with Dr Malcolm Coulthard, an eminent consultant paediatric nephrologist who plays a key advisory role on the DUTY Study Steering Committee.

How Are We Doing?

804 children have been consented so far, with 703 urines collected. That's a urine retrieval rate of 88%!

The Cardiff centre is significantly ahead of target while the study as a whole is well on target with 2,731 recruits and an 88% sample rate.

So here's a Big Shout Out to all our recruiters.

Thank you all so much, your hard work is greatly appreciated!

Introducing Helen Thompson-Jones, Option 1 Recruiter, NISCHR CRC, West Wales.

Helen is DUTY's new kid on the block…….

Q: How will DUTY help you in the future? As the newest member of the research team being involved in DUTY is really helping me become familiar with the way in which clinical trials work. It has been a steep learning curve and I have no doubt this will benefit me in future research projects I become involved with. I have no previous experience in primary care and hopefully I will be able to become involved in further research in this area.

Q: What impact do you anticipate DUTY will have on UTI diagnosis in the future? I hope it will make diagnosis of UTI's simpler and quicker and help reduce the number of children who experience problems in later life due to UTI's.

Q: What do you think are the main challenges for the study? I think the main challenges for the duty study are obtaining urine samples and a possible tail off in recruitment during the summer months

Q: What are the main challenges for you? I think the main challenges for me are obtaining the urine sample once the child has left the GP surgery, especially as my map reading skills leave a lot to be desired, and keeping up with my previous colleague's 100% urine collection rate!

Q: What tips do you have for successful recruitment? Build a good relationship with parents and children and also be prepared to go out and about to collect urine samples.

Important Information for Recruiters:-

- **Ensure participants are aware a member of the study team may contact them for the 14 Day follow up interviews. We are also currently looking into providing an additional £5 voucher for their time. Watch this space for further info.**
- **Take care when recruiting participants with English as their 2nd language; if they have difficulty in the consultation they will have difficulty with the follow up. Interpreter's may need to be involved; so make a note of their primary language on section 2 of the CRF and in the free text box online.**
- **Don't shred or discard CRF's. Post them to us or keep them in the site files.**
- **Do take the time to check CRF's are complete and correct with ALL required data; this includes site & PID numbers, ethnicity, immediate/delayed script's, etc. Also check urine reports have PID numbers before you fax them to us.**
- **Please ensure that you are putting DUTY stickers on everything - urine containers, lab request forms, etc. Without a sticker, labs will not identify the sample as a DUTY sample.**

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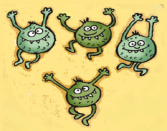

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An Interview with Dr Malcolm Couthard:

Q. Can you tell us about your background? I trained as a children's kidney doctor at Great Ormond Street and Guys Hospitals, and was appointed to the first post created in Newcastle in 1995. By the time I retired in 2009, the Newcastle children's kidney unit was a busy department with special interests in kidney transplants and UTIs, and lots of research activity.

I have always enjoyed research. I did a PhD in the ways that preterm babies' kidneys work, and have always been interested in how children's kidneys handle salt and water. We built the first haemodialysis machine designed for very small babies, and now that I have retired from day-to-day clinical work I have been able to develop this into a state-of-the-art machine which we expect to be in production fairly soon.

Q. What role do you play in the DUTY study? I have a big interest in the diagnosis and treatment of urinary tract infections (UTIs) in children. By reading and repeating some of the original research on testing urine, I have uncovered a number of widespread misunderstandings about the best ways to collect urines and test for UTIs. Some of these have now become falsely incorporated into modern day standard practice, and cause great confusion.

I have been asked to help oversee the science of the DUTY study, and bring in some of these issues. I am delighted to do this because it is a big and important study.

Q. How do you think the DUTY study will add value to clinical practice? There is great controversy about the best way to look after children who suffer from UTIs. But first, you have to make the right diagnosis. This study will help to address this important first step.

Q. What do you think are the main challenges for this study? To make sure that every child with a UTI has it diagnosed, it is necessary for nurses and doctors in primary care to think about the possibility of a UTI whenever they see an unwell child with unexplained symptoms. On the other hand, it is unrealistic to collect and culture urine samples from dozens of children for every child who turns out to have a UTI. The DUTY study is designed to help decide a sensible balance of which children do and which children do not need to be tested.

The biggest challenge to answering this question correctly is that standard ways of testing for UTIs have a significant false-positive rate, and that this rate is quite close to the frequency with which this study is likely to detect positive results. In other words, with standard testing methods, if you check about 20 infants who do not have a UTI, the laboratory will tell you that 1 of them does have one, because that is the error of the technique.

Trying to sort out which of the DUTY study children with a positive result really have UTIs and which ones don't will be difficult if only standard methods were used. This is especially the case because we are deliberately planning to test lots of children, and do not expect a very large proportion to be genuinely positive.

At the moment, we are testing ways of overcoming this problem, by doing more detailed ways of testing for UTIs during the DUTY study.

Q. What is your aspiration for the development of the NHS over the next 10 years? Like many others who work in the NHS, I am extremely worried that the reforms being considered by the Coalition Government are in truth an untested experiment, with no evidence base, which has the potential to destroy some of the most important elements of the service as we have known it since 1948. I fear that they will allow privatisation by the back door, and that the NHS could be driven by competition based on cost, with quality issues being given little more than lip service. For now, I would settle for the NHS still being recognisable in 10 years time, and for it not to have morphed into the US model of healthcare.

For further information about the first haemodialysis machine for babies, go to http://news.bbc.co.uk/1 hi/7542404.stm.