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## Welcome

This is the first of hopefully a regular publication to keep you updated about the activities of the network and future developments. Effective communication is at the heart of delivering a safe and reliable service and hopefully this newsletter will help in the process.

Although we have now been meeting as a group for a little over 3 years the network is still in its infancy and we need to get feedback to make sure it works for everyone involved. We particularly want to get patients and families involved in helping formulate strategies for delivering the service that they want. Obviously there are limitations created by the environment in which we work but dialogue which has now been started with the Welsh Health Specialised Services Committee (WHSSC) is an opportunity to try and get things right. It is important that everyone involved in providing care to children with kidney disease in Wales and their families feels that their needs are being recognised and this is best done through the network.

Finally, I do not want to have to write everything for these newsletters so please let me know if you have something you wish to contribute.

Graham Smith

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## The website

The network has a website that hopefully provides useful information for both professionals and patients and their carers. It can be accessed by going to <http://www.wcpn.wales.nhs.uk>.

The website tries to reflect the fact that services for children in Wales are provided by paediatric nephrology centres in Cardiff, Liverpool, Birmingham and Bristol.

If you have suggestions about changes that you think are needed to the website or additions that should be made then e mail Graham Smith at [Graham.Smith3@wales.nhs.uk](mailto:Graham.Smith3@wales.nhs.uk).

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## Officers

The network has been chaired since its inception by Dr Michelle James-Ellison. She is handing this role on and we must all thank her for the hard work she has put in to get us started.

The role of Secretary is being taken up by Dr Pugazh Kandaswamy who is based at Neville Hall Hospital.

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## Educational meetings

The next network meeting will be alongside an educational session to be held on Friday, 1<sup>st</sup> December 2017. The venue is the Education Centre lecture

theatre at the Princess of Wales Hospital in Bridgend. Make sure you keep the date free.

There is a Nephrology Day for General Paediatricians on Friday 17<sup>th</sup> November 2017 run by the Institute of Child Health in London which is an excellent learning opportunity for paediatricians with an interest in nephrology. For further information go to their website at <http://www.ucl.ac.uk/ich/short-courses-events/short-courses-events-publication/nephrology-day-general-paediatricians/nov2017>

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## Transition to adult care

One of the most challenging aspects of caring for children with chronic diseases is managing the transfer of their care from the paediatric to the adult team. Various methods are used to try and facilitate this process and our unit has the benefit of a youth worker, Shaun Thomas, who works across the Cardiff and Swansea unit.

We are also using the Ready Steady Go programme developed in Southampton to provide a structured transition process. It is a generic product applicable to any chronic illness and further information can be obtained at

<http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>

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## Research

With the increasing emphasis on evidence based practice, clinical research is influencing our practice in many fields of medicine including paediatric nephrology. We are participating in selected national and international multicentre clinical studies addressing important clinical questions:

### **1. Prednos 2 - EudraCT 2012-003476-39**

PREDNOS 2 is a national multicentre double blind randomised controlled trial of short course daily prednisolone therapy at the time of upper respiratory tract infection in children with relapsing steroid sensitive nephrotic syndrome (SSNS).

Aim of the study: To evaluate the effectiveness of a six day course of daily prednisolone therapy at the time of URTI in reducing the development of subsequent nephrotic syndrome relapse in children with relapsing SSNS.

Inclusion criteria: Subjects aged over 1 year and less than 19 years will be eligible for inclusion if they have relapsing SSNS, defined as having experienced 2 or more relapses in the preceding 12 months.

Further details can be obtained at

<http://www.birmingham.ac.uk/research/activity/mds/trials/bctu/trials/renal/prednos2/index.aspx>

### **2. Study of Membranoproliferative glomerulonephritis (MPGN), dense deposit disease (DDD) and C3 glomerulopathy(C3G)**

Aim of the study: To discover whether problems with the immune system are key in causing MPGN/DDD, to build a group of patients with these rare diseases in order to test new treatments and thirdly to look for signs that might predict a good or bad outcome.

Participants' clinical information is entered into the secure RaDaR database and a small amount of extra blood is sent every 6-12 months to expert laboratories in the UK to look at aspects of the immune system. The original kidney biopsy is reviewed by a panel of pathologists to see if there are any

links between the biopsy features and the clinical course of the patient. It is hoped this will provide vital information to guide clinical trials of new treatments for MPGN and C3G.

Further details can be obtained from <http://rarerenal.org/rare-disease-groups/mpgn-ddd-and-c3-glomerulopathy-rdg/#>

**We are actively seeking participants for the following new studies which are expected to open for recruitment locally from November 2017.**

### **3. Eculizumab in Shiga-Toxin producing Escherichia Coli Haemolytic Uraemic Syndrome (ECUSTEC) study**

Aim of the study: To determine whether Eculizumab reduces the severity of Shiga-Toxin producing E. Coli Haemolytic Uraemic Syndrome (STEC-HUS) in children.

Trial design: Randomised, parallel group, double blind, placebo-controlled trial.

Study population: Patients over 6 months of age and less than 19 years, weighing  $\geq 5$  kg with a diagnosis of STEC-HUS.

Further details can be obtained from

<http://www.birmingham.ac.uk/research/activity/mds/trials/bctu/trials/renal/ECUSTEC/index.aspx>

### **4. National Study of Nephrotic Syndrome (NephroS) study**

This is a prospective multi-centre observational study to improve the understanding of nephrotic syndrome and aid the development of new treatments. In particular the objective is to provide a comprehensive genotype/phenotype correlation of the disease, to identify a common disease mechanism in this group of patients, which would form the basis for an interventional clinical trial of novel pharmaceutical agents and to study the recurrence of the disease post-transplantation (as seen in some patients).

Inclusion criteria: Children and adults (no age restrictions) with Idiopathic Nephrotic Syndrome

Further details can be obtained from <http://rarerenal.org/clinician-information/nephrotic-syndrome-clinician-information/nephros-study/>

*For further details about any of these studies including study recruitment eligibilities please contact [Shivaram Hegde](#) or any of his colleagues at the Childrens' Kidney Centre, UHW.*

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## **Guidelines**

It should be recognised that children in Wales receive tertiary paediatric nephrology care from a number of centres based on geography. These include University Hospital of Wales, Cardiff; Alder Hey Children's Hospital, Liverpool; Birmingham Children's Hospital and Bristol Children's Hospital.

The guidelines produced by the staff at UHW are available on the WCNPN website at <http://www.wcnpn.wales.nhs.uk/guidelines>