10<sup>th</sup> August 2018 Newsletter Number 3

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## Notes from the Chair

As with so many good ideas in the NHS keeping people motivated seems to be the biggest battle. We held a Business meeting on 9 July but unfortunately many people were unavailable and there were just 4 participants. We will aim to try and give more notice of these meetings and remember that you can participate from your office if you have Skype for Business or access to video conferencing. Minutes of the meeting are on the website.

I remain determined to support your ability to deliver as much of the care of our shared patients locally. This is through improved communication and increasing the provision of joint clinics with one of the specialist paediatric nephrologists. If there are other resources that are needed then please raise this with me.

As we enjoy the best summer in memory the temperatures seem to be drying out our patients as well as the crops. Raised creatinines demand a little extra water although children don't get quite so dry nowadays playing on their Gameboys as they did in the past outside playing football.

Our next gathering will be the Study Day in November with an accompanying short business meeting immediately before. I look forward to seeing as many of you as possible there.

Graham Smith

# The website

Do not forget to make use of the website at: <a href="http://www.wcpn.wales.nhs.uk">http://www.wcpn.wales.nhs.uk</a>.

It is continually updated and provides useful telephone numbers in the Contacts section as well as Guidelines relevant to secondary care.

If you have suggestions about any other 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.

## **Officers**

If you have any issues you wish to raise in relation to paediatric nephrology in Wales either contact Dr Graham Smith, consultant paediatric nephrologist at UHW or Dr Pugazh Kandaswamy who is based at Neville Hall Hospital.

# **Educational meetings**

The November Study Day is planned for Friday 9<sup>th</sup> November in the Postgraduate Centre at the Princess of Wales Hospital, Bridgend. More details will follow but please put the date in your diary. In addition information about other meetings which may be of interest to SPIN doctors are also posted on the meetings page of the website at <a href="http://www.wcnpn.wales.nhs.uk/future-dates">http://www.wcnpn.wales.nhs.uk/future-dates</a>

#### Website

http://www.wcnpn.wales.nhs.uk/

The Institute of Child Health in London are holding their Nephrology Day for Paediatricians on Friday, 23<sup>rd</sup> November. This one day course aims to give a full overview of paediatric nephrology by selecting different themes each year and presenting them in a way which will be suitable for general paediatricians. Further information is available at https://www.ucl.ac.uk/child-health/events/2018/nov/nephrology-day-general-paediatricians

#### Transition to adult care

The inaugral Young Adults clinic in Morriston Hospital will be held on Tuesday,  $21^{st}$  August. The first clinic is aimed at patients on the books in Morriston but the hope in the future is to also see patients from West Wales who will come under Swansea for their adult care. If you would like to refer patients contact Michelle James-Ellison or Graham Smith.

#### Research

We are currently recruiting patients for the ECUSTEC study looking at the early administration of eculizumab in diarrhoea-associated HUS. Patients with suspected HUS should be discussed promptly with the appropriate paediatric nephrology centre to fulfil study requirements.

The NephroS study is collecting data and clinical samples on patients with idiopathic nephrotic syndrome and all patients are elligible.

We are also continuing to recruit patients for the PREDNOS2 study looking at short course daily prednisolone therapy at the time of upper respiratory tract infection in children with relapsing steroid sensitive nephrotic syndrome.

For further details about any of the studies including study recruitment eligibilities please contact Shivaram Hegde or any of his colleagues at the Childrens' Kidney Centre, UHW or colleagues in Alder Hey Children's Hospital for patients in North Wales.