

## In This Issue

- Notes from the Chair
- The website
- Educational meetings
- Transition to adult care
- Research

## Notes from the Chair

I remain committed to working with you to ensure that there is equitable, high quality care for children with kidney disease across Wales. It is disappointing that the interest shown by WHSSC last year seems to have waned. As commissioners of the service, I would expect them to want to ensure the service they are purchasing meets the standards expected. Unfortunately our patients do not vote.

We held our Study Day in November and I was pleased to be able to present awards for excellent presentations from junior staff. We had a guest lecture from Professor Richard Coward on stone disease and I know those who attended enjoyed the day. The slides from the talks are available from the website. I would ask you to encourage your colleagues and junior staff to look out for the meeting at the end of this year. We will potentially be looking at the subject of Transition to adult services and will be looking to involve other paediatric specialties to hopefully share good practice.

Pugazh Kandaswamy is currently looking to identify a day in May on which to hold our Spring business meeting. The intention is to hold this via Skype as the majority of you now have access to this and it should enable more to participate. Please let Pugazh know your availability.

Graham Smith

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## The website

Do not forget to check the website at <http://www.wcnpn.wales.nhs.uk/>

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## Educational meetings

Meetings which might be of interest are posted on the website at <http://www.wcnpn.wales.nhs.uk/future-dates>.

The annual 5 day course run at the Institute of Child Health in London will take place between Monday 1st April and Friday 5th April 2019. It is of relevance to General Paediatricians, Paediatricians with an interest in Nephrology and Paediatric Nephrologists in training. Further information is available at <https://www.ucl.ac.uk/child-health/events/2019/apr/2019-continuing-education-programme-nephrology-week>

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## Transition to adult care

As I have mentioned above, we plan to use our Study Day this year to look at this topic. We have now held our second young adult clinic in Morriston Hospital, in the newly refurbished adult renal department.

Our ability to address the needs of these patients has been greatly enhanced in the last 3 years by the appointment of a Renal Youth Worker, Shaun Thomas. He works between Cardiff and Swansea and if anyone thinks he can

### Website

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

help with a young renal patient you can e mail him at [Shaun.Thomas2@wales.nhs.uk](mailto:Shaun.Thomas2@wales.nhs.uk)

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## Research

Dr Shiv Hegde presented the results of the PREDNOS study, which involved children from Wales, at the meeting in November.

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 whether steroid sensitive or resistant. This is purely a genetic study trying to identify genes associated with idiopathic nephrotic syndrome. It is important we recruit as many children as possible in order to add power to the study. For further information contact Shiv Hegde.

PREDNOS2 has finished recruitment.

*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.*