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## Notes from the Chair

Just as I am considering whether the purchase of a pair of trousers this morning with a 36" waist was perhaps over-optimistic I feel that I should get on with another newsletter, having promised in September that there would be a regular publication to help keep everyone engaged with the network. It remains key to the success of our service that everyone feels they have a means of raising issues in order for us to support both providers and receivers of care. As many of you know, the setting up of this network has been an aim of mine for the last 15 years and I am honoured to now be chairing it. Michelle has done a great job in getting us to this point and I would like to take this opportunity to thank her for all her hard work. We now need to strengthen these foundations. Please get in touch with me if you think we need to be doing anything differently.

It was great to see so many people at the Study Day at Bridgend at the beginning of December and I think everyone found it informative. Many thanks to all the speakers and to Alexion for sponsoring the event. It would be great to see more juniors and the plan for the next Study Day is to have a prize for the best Junior Case Presentation.

We intend to have a Business meeting in May and Pugazh will/has sent out a request for you to let him know your availability. It is important to have a representative from each hospital, particularly in order to discuss future developments of the peripheral clinics. It is also important to spread the word to other members of your team involved in the care of children with kidney disease e.g. dieticians, nurses who are welcome to attend these meetings.

It has gone rather quiet on the WHSSC front. There have been a number of personnel changes in their organisation and we are continuing to try and secure the intended financial investment in our service. This will hopefully allow us to increase the service we can deliver through our peripheral clinics.

We are pleased to announce that funding has been secured from Kidney Wales for a dedicated renal psychologist. This service was lost following the retirement of Anna Brazier and this appointment should improve the support we can give patients and their families, particularly those living outside Cardiff.

You may also be interested to learn that it has been decided to try and rationalise the protocols used by the centres undertaking paediatric renal transplantation. At present each unit has their own protocol and this is an important development. When the final details are sorted out it will be posted on the website. Obviously it does not have a direct impact on us as our transplants are carried out in England but it is a step forward in being able to look at outcomes.

Finally, can I reiterate that 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.

### Website

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

Graham Smith

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## The website

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

I am continuing to adapt it so that it reflects the service in Wales, particularly the North / South split.

I have added some more guidelines which will hopefully be of use to staff.

Please take a look at the contact page related to your hospital and let Graham Smith know if there is any other information that could be added in relation to the local service provided.

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](mailto:Graham.Smith3@wales.nhs.uk).

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## Officers

Following the standing down of Michelle James-Ellison as Chair, this role has been taken up by Dr Graham Smith, consultant paediatric nephrologist at UHW.

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

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## Educational meetings

A very successful Study Day was held in Bridgend on 1<sup>st</sup> December 2017. Copies of the slides used for the presentations are available on the website at <http://www.wcpn.wales.nhs.uk/study-day-2017>

We will be holding another Study Day at the end of 2018. Details will be posted on the website. In addition information about other meetings which may be of interest to SPIN doctors will also be posted on the meetings page of the website at <http://www.wcpn.wales.nhs.uk/future-dates>

The Institute of Child Health in London are holding their annual Continuing Education Programme in Nephrology Week in April. Details are available on the website. You may find individual days of interest rather than the whole week. Please take a look.

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## Transition to adult care

The website has been updated to reflect practices in North and South Wales. Not surprisingly the key objectives in both areas are very similar and relevant documents are available on the website.

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## Research

An update on the research programs currently being undertaken in Cardiff was given by Shiv at the recent Study Day. We are still in the process of finalising arrangements for the Ecustec trial and you will be informed when we are able to recruit patients.

*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.*