Meeting Notes - 01.12.2017

Participants
- Michelle James-Ellison (MJE)
- Katherine Wooding (KW)
- Graham Smith (GS)
- Shivaram Hegde (SH)
- Pugazh Kandaswamy (PK)
- Torsten Hildebrandt (TH)
- Judith VanDerVoort (JvV)
- Michelle Barber (MB)
- Marcus Andrews (MA)
- Annabel Lochrane (AL)

Apologies
- Jaya Natarajan (JN)
- Madalitso Kubwalo (MK)
- Toni Williams (TW)
- Saurabh Patwardhan (SP)
- Raj Krishnan (RK)
- Markus Hesseling (MH)

	Agenda Item and action	Action by
1	**Welcome and apologies**	
2	**Minutes of last network meeting**. Matters Arising – all in agenda.	
3	**Constitution** i. Sign off constitution - Amendments discussed and agreed at August meeting have been incorporated into document: o Naming of network as Welsh Clinical Network for Paediatric Nephrology to represent inclusion of service across Wales with recognition of the different arrangements between North and South Wales. These differences noted in the constitution. To send a copy of revised constitution to WHSCC Women and Child Health Clinical. Copy of constitution available on WCNPN website ii. Officers to be appointed - Chair – Dr Graham Smith has been appointed as Chair to run in office for 3 years until October 2020. - Secretary - Dr Pugazh Kandaswamy has taken up the post of secretary and he too will be in office until October 2020. iii. Patient engagement Further thought to be given to recruiting patients/parents to contribute to Network activities. In particular need their input into how we develop peripheral clinics. Will need to approach families in clinics. Will advertise the website and the ability to feedback through this medium. WKPA has advertised this but no response so far. Utilise patient experience questionnaire available or RCPCH website and modify for feedback from clinics as suggested by RK at last meeting. Consult MH	**GS** **GS**

4	**Peripheral clinics** Wish to continue to develop peripheral clinics to maximise the benefits for patients. Plans: - Continue to roll out Vital Data. Currently installed in Abergavenny and Morriston clinics. SPIN consultants need to liaise either with their Cardiff consultant or GS or Gary Hunter. - Looking to increase frequency of Morriston clinic to 2 monthly. - Looking to amalgamate the clinics in Hywel Dda onto one site. This clinic would take place 2 monthly thereby reducing the need for patients to travel to Cardiff. A site for this combined clinic needs to be decided. - Cardiff unit working to strengthen its workforce in order to be able to take non-medical staff to peripheral clinics. Last Morriston clinic attended by Cardiff nurse and Youth Worker. This will helpfully further reduce the need for patients to travel to Cardiff. -	**GS** **GS MJE** **JvV RK TW**
5	**Transition to Adult Care Clinic Proposals** Currently SH running a transition clinic in Cardiff which has been in place for over 10 years. Plans to duplicate this in Morriston in association with one of the adult nephrologists, Dr Clare Palmer. As patients from Hywel Dda will receive their care as adults from the Morriston team it was agreed that Hywel Dda patients aged 16+ should be identified and referred to this clinic once it is set up. GS highlighted use of the ReadySteadyGo program by the Cardiff team to provide a structure for the transition process which is started around 13 years of age. This is a generic program which can be used for all chronic diseases. A link is available on the website. Recognised at last meeting that arrangements different for North Wales. This needs to be incorporated on to the website page dealing with transition. GS still waiting to hear from the North Wales team as to what they would like added to the page.	**MJE GS** **TW JvV RK** **MH MK NN GS**
6	**Website** Website up and running. TH has agreed to act as co-owner of the website should GS be incapacitated. Details about the website to be communicated to families. Cardiff team plan to put details on clinic letters.	**GS**
7	**Guidelines on website** Guidelines now divided into those aimed at secondary level care and those aimed at tertiary level care. TH raised the need to keep the guidelines up to date and whether use of nationally agreed guidelines would help manage this issue. The website states clearly that the guidelines on the website have been developed by the team in South Wales and that the link of North Wales.	

8	**Paediatric nephrology Studies and Research** SH to present details in Study Day. Slides will be available on the website.	**SH**
9	**Audit** Carried over	
10	**Radiology** Carried over	
11	**Study day** Alexion sponsored study day to follow this meeting. Thanks to Alexion for sponsoring the food and the travel costs of the principal speaker, Dr David Milford. Good to see two trainee presentations in the program.	
12	**AOB** MJE raised the issue of the high cost of the liquid formulation of nitrofurantoin (£14.90 for the liquid form v £0.47 for a tablet for a 50mg dose) and pressure from pharmacies to avoid its use. The options are to crush a tablet and suspend it in water or use an alternative antibiotic. The first might cause problems when using a fraction of the whole tablet and whether the suspension is evenly mixed if done at home. Nitrofurantoin is an ideal antibiotic for prophylaxis as it is excreted in the urine and has a low rate of resistance - only 1.2% of urinary coliforms isolated from community acquired UTIs in children under 15 years in Wales in 2016. This compares with a rate of 31% for trimethoprim. The other proposed prophylactic agent is cefalexin but GS raised concerns about the development of resistance with long term cephalosporin use. GS has contacted microbiology for confirmation of this belief. Currently only 5.5% of isolates are resistant to cephalexin. Response from Dr Robin Howe at Public Health Wales – "It is indeed more likely that resistant organisms would arise than with nitrofurantoin, due to the higher existing levels of resistance in the community, and the fact that cefalexin gets into stool and exerts a selective pressure, whereas nitrofurantoin doesn't get into stool to any great extent. However, I still think that cefalexin would be/is a reasonable option for prophylaxis." GS stated that the current guidelines about the use of prophylactic antibiotics means that we are not using anywhere near as much as previously and now only in patients with recurrent problematic UTIs and not routinely in children with vesicouretric reflux. GS has discussed this with the paediatric renal pharmacist in UHW and they will continue to support its use where it is felt necessary. GS will send a response on behalf of the WCNPN.	**GS**
13	**Date and time and venue next meeting** To be confirmed.	