

+ Meeting Notes - 09.07.2018

Participants

- Graham Smith (GS)
- Pugazh Kandaswamy (PK)
- Judith VanDerVoort (JvV)
- Markus Hesselning (MH)

Apologies

- Raj Krishnan (RK)
- Michelle James-Ellison (MJE)
- Torsten Hildebrandt (TH)
- Kathryn Lewis (KL)
- Shiv Hegde (SH)

	Agenda Item and action	Action by
1	Welcome and apologies	
	Due to the presence of only four participants an informal discussion took place covering the following topics:	
2	<p>Peripheral clinics</p> <p>Discussions have taken place regarding the peripheral clinics in Hywel Dda with a draft plan to centralise the site for these clinics in Carmarthen drawing patients from Bronglais and Withybush. This should result in an increase in the frequency of clinics and hopefully reduce the number of visits patients will need to make to Cardiff. Further talks will take place between Drs Krishnan and van der Voort from Cardiff and Dr Pitchaikani the local clinical lead.</p>	<p>RK</p> <p>JvdV</p>
3	<p>Transition to Adult Care Clinic Proposals</p> <p>A young peoples' clinic is planned to take place in Morriston Hospital in August in conjunction with one of the adult nephrologists. The hope is to draw in patients from Bridgend and Hywel Dda who will be receiving their adult care from the team in Swansea. Discussions were had about setting up a young peoples' clinic in Gwent. GS and PK will discuss with the nephrologists responsible for adult renal care in Newport. These are consultants who travel over from Cardiff.</p>	<p>GS</p> <p>MJE</p> <p>GS PK</p>
4	<p>Renal Study Day</p> <p>The plan is to have another study day in November. This will be held in the Postgraduate Centre in the Princess of Wales Hospital in Bridgend. JvdV felt that this would also allow us to broadcast the lectures to people unable to attend via Panopti. PK will look into this. GS proposed that the main thrust of the Study Day could be about Transition and we could invite adult colleagues to give their perspective alongside a patient view from one of our patients who now works with our Youth Worker. We could invite Dr Nagra from Southampton to tell us about the Ready Steady Go program we are using in Cardiff. This is not disease specific although Dr Nagra is a paediatric nephrologist. The hope would be to invite other specialties to attend e.g. diabetes and epilepsy and share their experiences of transition.</p> <p>Alexion have agreed to sponsor the meeting again.</p> <p>It was felt that a Friday would be suitable and we will ensure it does not clash with other meetings. PK will identify the best date.</p>	<p>PK</p> <p>GS</p> <p>PK</p>
5	<p>AOB</p> <p>MH requested advice about the follow up of patients with renal scarring. GS and JvdV</p>	

	<p>agreed that the question of whether scarring was unilateral or bilateral was the most important criterion. If the child has a normal kidney with compensatory hypertrophy, if the function in the contra-lateral kidney is significant, long term follow up requires just an annual blood pressure check and urine dipstick for protein. The risk of hypertension is probably <10%. If scarring is bilateral there is a risk of long term renal dysfunction and closer follow up is required certainly until the child has completed puberty and their growth spurt.</p> <p>This question raised the issue of which patients, when they become an adult, will continue to be followed up in a nephrology clinic and which will receive GP follow up. This fits in with adult input to the Study Day and GS will look at drawing up some criteria as to which patients will continue to receive specialist follow up so we are able to prepare patients accordingly.</p>	GS
6	<p>Next meeting A business meeting will precede the Study Day in November. The date of the study day will be announced shortly.</p>	PK

Graham Smith 15.07.2018