

+ Meeting Notes - 25.09.2019

Participants

- Graham Smith (GS)
- Pugazh Kandaswamy (PK)
- Michelle James-Ellison (MJE)
- Torsten Hildebrandt (TH)
- Judith van der Voort (JV)
- Markus Hesselning (MH)
- Isabel Fraser (IF)
- Nicole Parish (NP)

Apologies

- Ezzat Afifi (EA)
- Aftab Murtaza

	Agenda Item and action	Action by
1	Welcome and apologies	
2	Minutes of last network meeting Matters Arising – all in agenda.	
3	<p>Future meetings</p> <p>Following poor turnouts to previous meetings it was decided that this meeting would be held via Skype. This has improved the attendance and was felt by those present to be a positive initiative. Obviously those present represent a highly selected group. A number of other people had indicated their intention to log in but did not do so. GS will try and identify why. The consensus was that this was a convenient method of holding the meeting. It is unfortunate that EA cannot get access to Skype despite its widespread use and promotion within Health Boards. Hopefully he can get this issue resolved.</p> <p>The intention is to have a biannual business meeting and an annual Study day as previously. Unfortunately the attendance at the last study day in November last year was disappointing. It was agreed that it was important to maintain this event and it might be better suited to a half-day program tied into an educational event for juniors. A greater emphasis on more generic topics was suggested e.g. procedural pain management in children. A venue will be selected which enables remote access to the event.</p>	<p>GS</p> <p>GS</p>
4	<p>Peripheral clinics</p> <p>Discussions were had regarding the following peripheral clinics:</p> <p>Bridgend: Reorganisation of Health Boards has not directly influenced care of renal patients in Bridgend. Potential for collaboration between TH and EA in the future.</p> <p>TH now has access to Vital Data in his office and in clinic. Relies primarily on WCP.</p> <p>Morriston: The Morriston clinic remains busy taking place every 4 months. Recognised the input that MJE has in caring for tertiary level patients. This is duplicated by a number of other DGH paediatricians reflecting their greater comfort with these patients. The ability to increase the frequency of the Morriston clinic is limited by other commitments.</p>	TH

	<p>Neville Hall: 3 monthly clinic with PK and GS with increasing numbers of patients being seen.</p> <p>Both PK and MJE described the merits of a peripheral urology/neuropathic bladder clinic. This has been discussed by MJE with Mrs Abyankar for Morriston and the hope is that this will be started in the near future. With the appointment of Mr Awad as a paediatric urologist in UHW and the imminent start of a replacement for Mr Hutton it was felt that an approach to consider a similar clinic for Gwent would be appropriate.</p> <p>As previously suggested we will approach the paediatric urology team to join this group.</p> <p>Hywel Dda: Previous discussions have focussed on amalgamating the clinics currently held in Carmarthen, Withybush and Aberystwyth in order to make more frequent clinics worthwhile. JV has taken over the Bronglais clinic from Dr Krishnan but this only happens every 6 months making it difficult to follow patients and there is no identified paediatrician responsible for patients locally. Dr Toni Williams has moved from Carmarthen to Swansea and there is currently no local paediatrician specifically responsible for renal patients. Dr Kathryn Lewis has taken up the role in Withybush Hospital but JV has not been able to get engagement from the Hywel Dda management to consolidate the service. GS will make contact on behalf of WCNPN to try and push towards the amalgamation of clinics so patients can be seen more frequently where necessary (aim for a 3 monthly clinic) with the withdrawal of a specific clinic in Aberystwyth. GS will also ask for the identification of a lead paediatrician for nephrology in Carmarthen unless it is possible for Kathryn Lewis to take responsibility across Hywel Dda.</p> <p>Cwm Taf: Dr Krishnan has taken over this clinic from JV and runs it with EA. Unfortunately neither were present. EA has informed GS that his Health Board have not given him access to Skype but he will make further enquiries. He still does not have access to Vital Data. There are some issues with the IT system in Cwm Taf and EA should make further enquires.</p> <p>North Wales: Currently MH looks after Glan Clwyd Hospital, Dr Nick Nelhans in Wrexham Maelor Hospital and Dr Mada Kubwalo in Ysbyty Gwynedd Hospital. Joint clinics are run with Dr Henry Morgan in Glan Clwyd Hospital and Wrexham Maelor Hospital and with Dr Richard Holt in Ysbyty Gwynedd Hospital. There seems to be differences in the complexities of patients that paediatricians are happy to manage locally reflecting local expertise. There are no IT links between North Wales and Alder Hey although MH is in contact with the Share to Care team from Alder Hey. The main obstacle is the fire wall between England and Wales which causes similar problems with links between Cardiff and Bristol. Hopefully information sharing can be improved. MH informed the group that Alder Hey are setting up their own renal network which he would be part of. It is hoped that he can maintain contact with the WCNPN.</p> <p>The interaction between IF and paediatric dietitians in local hospitals was discussed. The aim is that local dietitians can help manage specific nutritional requirements of children with renal disease in conjunction with IF and in the case of Swansea, the dietitians supporting the adult renal service.</p>	<p>MJE</p> <p>PK</p> <p>GS</p> <p>GS</p> <p>EA</p> <p>MH</p>
--	--	--

3

	2 nd October 2019.	
7	Website GS continues to maintain the website. Feedback is encouraged.	GS
8	Guidelines Guidelines are available on the website and the scope of the guidelines will be expanded.	
9	Paediatric nephrology Studies and Research The main research activity at present is the ECUSTEC study looking at the role of eculizumab in D+HUS. Paediatricians are encouraged to refer any suspected cases promptly to facilitate enrolment. Cardiff have had a number of cases recently and have been able to recruit a couple of patients to the trial.	
10	Audit MJE and PK will take forward an audit of renal stone disease in Welsh children. It was felt that it would be beneficial to approach Mr Awad (consultant paediatric urologist, UHW) for support in this project.	MJE PK
12	AOB The benefit of involving parents/patients in the network has been discussed previously but not materialised. NP is holding a coffee morning for parents on 17 th October and this might be an opportunity to seek interest in becoming involved in the network.	GS NP
13	Next meeting The next meeting will be a study day, date to be confirmed.	GS

Graham Smith 01.10.2019