

**Venue: Multi Prof Education Centre POW Hospital, Bridgend**

*Attended by*

- Dr Torsten Hildebrandt  
Consultant Paediatrician
- Dr Shiv Hegde  
Consultant Paediatric Nephrologist
- Dr Graham Smith  
Consultant Paediatric Nephrologist
- Dr Jeya Natarajam  
Consultant Paediatrician
- Dr Michelle James-Ellison  
Consultant Paediatrician (Chair and taking notes)

*Apologies*

- Lynne Millar-Jones  
Consultant Paediatrician
- Dr Pramodh Vallabhenini  
Consultant Paediatrician
- Dr Kath Wooding  
Consultant Paediatrician
- Dr Judith van der Vort  
Consultant Paediatric Nephrologist

Via AV link Singleton Hospital Swansea for 1 hour

- Drs Puva Vamadevan (Ass Specialist)
- Dr Hari Harikrishnan (Staff Grade Paediatrician)

1. Welcome and apologies.
2. Notes of meeting Feb 25<sup>th</sup> 2014

***Accepted – no corrections.***

3. Matters Arising
  - a) Lynne and Jeya comment – no visiting nephrologists to Cwm Taf (Royal Glam or Merthyr) GS emphasised the need to have a point of contact for antenatally detected renal anomalies. Cwm taf recommended that Dr Al- Mufayar is Royal Glam neonatal lead and best point of contact.

***Plan – Action – Clarify DGH lead/contact who to write the letters to re: antenatal renal problems (MJE)***

b)NW – Dr. Markus Hesseling contacted and confirmed that Alder Hey is renal link hospital. Wishes to be kept updated of activities of this group

c) Discussed funding – no real funding source.

d) Name for group and Quorate? – no decision/consensus - ***Needs***

***further discussion***

4. Network Constitution – GS was thanked for drawing up draft constitution. Group went through draft line by line. Constitution to include Urologists. See alterations.

***Plan - for further distribution and adoption at next meeting (MJE)***

Discussed links with Bristol and Adult nephrologists; this maybe afford education and transition work opportunities. Discussed involvement in clinic uro-radiology UHW meetings via AV link or by invitation (proposed by TH).

***Plan - GS to explore further and report back***

Discussed how and whether to develop patient parent input to network – ***for further discussion.***

Starting up a Paeds Renal Database discussed. All Wales clinical portal and how to maximise/ optimise IT information across the network hospitals and area. AJ Forton (Cons Paed Respiriologist) has drawn up guidelines for UHW  
**Plan - GS to find out SharePoint guidelines and circulate/report back.**  
**Consider - IT to talk to group re database etc**

5. Clinical Governance (Standing item)  
a) Guidelines HSP (Dr Nootigattu not present) - Check GIT prednisolone dose with Paeds. SW gastroenterology network. Adjust investigations to clarify/clarity. Change to investigations then - Optional/second line

**Action MJE to do and send round to sign off draft**

- b) Next guidelines - ANHN; Sybil Barr Neonatologist drawing up guidelines - work in progress almost complete. GS suggested await these to shape our discussion.

**Action GS to bring along or circulate current UHW renal guidelines and debate which guidelines to review/revise next.**

- c) Await PREDNOS for shaping NS guidelines  
d) Ecolizumab – HUS – SH and GS say may be further information on its use in future.

**Plan as a Network education talk**

6. Audit and plans (??PUV) – All agreed await guidelines work first  
7. WPSU and Research - GS planning follow up HSP study  
Renal disease in DGH discussed or HTN  
8. Future Meetings and dates - next business meeting Lunchtime and afternoon in term time not holidays after March 2015. Aim for a presentation on HUS and ANHN and case presentation. Consider Royal Glam and POWH alternating venues for SWales group meetings  
9. Clinical issues  
Infokid leaflets and website noted [www.infoKID.org.uk](http://www.infoKID.org.uk)  
10. AOB  
○ TH discussed recent USS renal course he went on. USS trainers willing to come and host a course in Swales. Would enable a 1 stop shop for UTI patients investigation. Consider if enough people interested.  
○ Volunteers for sec / chair of group. MJE to continue as chair pro temp.  
Dates of next meeting? tbc

Michelle James-Ellison Jan 2015