

**Paediatric Renal Meeting and Exploring Paediatric Renal Network Notes
February 25th 2014**

Venue: Multi Prof Education Centre POW Hospital, Bridgend

Attended by

- Dr Nootigattu Tiru
Consultant Paediatrician
- Dr Shiv Hegde
Consultant Paediatric Nephrologist
- Dr P Kandaswamy
ST6 Paediatric Nephrology
- Ms Marie Williams
Paediatric Research Nurse
- Dr Kate Creese
Consultant Paediatrician
- Dr Graham Smith
Consultant Paediatric Nephrologist
- Dr V Kirupaalar
ST3 Paediatrics
- Dr Umer Ghafoor
Clinical Fellow Paediatrics
- Dr Jeya Natarajam
Consultant Paediatrician
- Dr Michelle James-Ellison
Consultant Paediatrician

Apologies

- Dr Torsten Hildebrandt
Consultant Paediatrician
- Dr Ekewa
Consultant Paediatrician
- Dr Max Nathan
Consultant Paediatrician
- Dr Rajesh Krishnan
Consultant Paediatric Nephrologist

1. Introduction

2. How the Diabetes Network and Paediatric Gastroenterology Network run - Strengths and Opportunities

i. Dr Nirupa D'Souza (Brecon Diabetes Group) Formed 1994 – 1995. Established Diabetes register and database. Agreed standards – audits and National audit involvement.

Strengths – clinician membership including psychologists and nurses.

Terms of Reference – constitution – amended 2013.

Officers – change q 3 yearly

- Chair
- Scientific organiser
- Treasurer
- Nurse rep

Officer for Implementation (New Post) - Driver – Diabetes delivery plan WG.

- a) Brecon Register – children with Diabetes Mellitus in Wales - Anonymised and consent. Maintained by funded administrative support (initially Novartis research money now WG). H. O'Connell in post – has previous experience of WPSU.
- b) Audit – All Wales plus epidemiological data. Aim – x1 All Wales audit per year
- c) Annual Scientific meeting x1 /yr. Endocrine/ diabetes themed – UK wide speakers and meal.
- d) Annual report for WG
- e) Projects
 - a. DKA Integrated Care Pathway – initial costs outlaid by Brecon Group.
 - b. Structured learning – started

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- f) Total Meetings x2 per year to start. Business meetings are videoconferenced.
- g) Finance for Education – support for companies. Question – conflict of interest.
No formal clinical network arrangements. Endocrine OOH advice via JB/JW/JG.

ii. Dr Mike Cosgrove (Gastro Network)

England and Scotland have MCN. Informal network across Wales (see slides) – emphasis on Clinical support and Service role of network – outreach clinics etc. Multidisciplinary. Strengths previous chair of BSPGHAN and 2 council members – so National representation

South Wales networks as no North Wales Rep.

- a) Standards 2008 CYPSS work
- b) Meet during work time x4 per year. MDT included
- c) Topics/ duties - Policies guidelines, parent leaflets, NPSA alerts and responses.
Difficult patient discuss management, Mortality and Morbidity meetings
- d) Education Study Day every 2-3 years.

3. Nephrotic Syndrome and PREDNOS study - Dr Shiv Hegde

PREDNOS 1. Still recruiting and in need of patients. Multicentre England and Wales newly diagnosed Nephrotic Syndrome Steroid management regimen.

PREDNOS 2 too determine if low dose steroids fro intercurrent infections reduce relapse rate.

4. NIHSCR and Paediatric Research Support Marie Williams Paeds Research Nurse

see presentation. Outlined Wales Paeds research support, how to access and role of research nurses.

5. Renal Audits

i. AKI – Dr Hegde 2005 – 2013. Causes of Aki and outcomes presenting to UHW.

Recommendations

- Avoid nephrotoxins
- Fluid resus and fluid repletion key intervention
- Early USS to exclude obstruction

ii. Immunisation and NS- Dr MJEllison. Catch up immunisations needed - immunisation info needed. Consider use of chickenpox vaccine.

6. HSP - update. Developing an HSP guideline – Dr Tiru presented ABHB HSP pathway.

Dr Tiru and all Group discussed and agreed.

- GP involvement in monitoring where possible
- Refer or discuss if BP raised or 2++ proteinuria
- First clinic follow-up 2-3 months. 95% of renal involvement will occur within first 6 weeks
- If clear at 6months and never any BP or urinalysis problems - then discharge.
- Few long term problems if well – remind females about PET in pregnancy.

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Action Dr Tiru to make changes and distribute for further comment. Look to adopt this by Network as DGH guidelines (not tertiary renal centre guidelines)

7. How a Paeds Renal Network might work? Strengths and Opportunities - all Group

Agreed - enough interest and commitment to take forward.

i. **Meetings** Discussed – start with SW and NW or SW alone. NW – natural alignment with Liverpool/Birmingham. DGH have strengthened links and outreach with English hospitals.

Action NW Outreach – MJE to check

ii. Current peripheral clinics – no clinic in Abergavenny. Need to identify and clarify Specialists/SPIN/enthusiastic link people.

Cons	Hospital/Clinic	Tertiary Cons Link
Dr Nootigattu Tiru	Aneurin Bevan UHB RGH Newport	Dr G Smith
	No Clinic in Abergavenny	
Dr Torsten Hildebrandt	Abertawe Bro Morr Uni Health Board (ABMUHB) POWH Bridgend	Dr S Hegde
Dr Michelle James-Ellison	Abertawe Bro Morg Uni Health Board (ABMUHB) Morriston	Dr S Hegde
Dr Ezzatt Affifi	Cwm Taf Merthyr	Dr Rajesh Krishnan
?Dr Veena Bisht	Hywel Da West Wales, Carmarthen	Dr Judith van der Vort
Dr Emeka Ikpakwu	Hywel Da, Bronglais, Aberystwyth	Dr Rajesh Krishnan
? Dr Lynne Millar-Jones	Cwm Taf Royal Glamorgan	? Dr Judith van der Vort

Action MJE to write and clarify

8. Summary and Next steps.

i. Discussed structure and frequency of meetings - Focus of network - Any financial support available to support network. Also Clinical Connections - North Wales?- adult links - Transition - CPD/Training/Education – encouraging trainees to join network . Research - Audit - WPSU Projects. BAPN direction - Parent support - Parent info leaflets.

Database value and format. What are other networks doing?

Action Shiv to enquire from English colleagues re their network activities, focus and direction

Action MJE to contact N Wales colleagues and ask their views/ invite them to join network

ii. Constitution/ TOR - ideas generated viz:

Aims should include:

- To develop consensus guidelines and referral patterns for common Paediatric renal and urological conditions
- To continuously improve standards of patient care
- All Wales audits and BAPN standards to standardise and critically review patient care.
- Encourage/ facilitate DGH participation in national UK audits and studies.

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- Opportunities to develop research experience and expertise in DGH
- Improve links between DGH and tertiary centre communication, info sharing, Transition etc.
- Include AHP – dieticians, CNS, continence nurses.
- Explore Database – e.g. NS database/ research
- Encourage develop study days in DGH and trainees to improve knowledge and disseminate good practice via e.g. Refresher courses. shared questions and radiology consensus
- Feedback to patients and responsive to patient safety issues
- Adopt or aspire to the CYPSS and Wales Renal NSF standards.

Steps

1. Identify Link Consultants
2. HSP Guideline Dr N Tiru to modify and send out HSP guidelines for feedback from DGH colleagues via their renal link.
3. Start with 2 x business meeting per year – via videoconference from POWH
4. x1 education afternoon (Sept 2014)
5. Avoid half term
6. Chair, Secretary and Notes/minute taker roles to rotate
7. Finance – any available via college or WPS – admin support and recognition
Action MJE to explore or write
8. Explore Pharmaceutical co to sponsor speakers. *Action All*

Education Session

A. Antenatal Hydronephrosis - postnatal management: an update.

- Dr Graham Smith need a contact point for DGH leads when children have antenatal renal lesions.

B. Case Presentations and discussion

- Dr V Kirupaalar,
- Dr Pugazh Kandaswamy

Michelle James-Ellison March 2014