



Paediatric Renal Network Steering Group
Monday 24th June 2013

Present: Martin Christian, Michelle West, Shelley Jepson, Pearl Pugh, Judith Hayes, Simon Rhodes

Apologies: Gail Moss, Mona Aslam

	Item	Discussion	Action
1.	Chairperson	Michelle agreed to act as Chair for the steering group in the future.	
2.	Matters arising	The terms of reference, guidelines for local clinicians and job descriptions for link nurses and dietitians have all been written. We have now agreed a logo which is being used. The website is looking good but we still need to look at the possibility of it being hosted outside NUH. Doncaster and West Suffolk new outreach clinics have commenced and are running well. There is a hold up with Bassetlaw although dates have been suggested. James Paget and Barnsley have some suggested dates but no agreement as yet.	To be agreed and signed off at business meeting in October. Logo needs adding to letterheads for EMEESY correspondence. Michelle will look at how other networks have their websites hosted.
3.	Review of secondment report	Simon was asked for his opinion and he had no comments at present. Michelle asked how widely it had been distributed. It has been sent to all medical, nursing and dietetic leads as well as senior management at NUH, the commissioning team, BAPN, Donal O'Donoghue and Beverley Matthews at NHS Kidney Care, NKF, Jacqueline Cornish and Ruth Bridgeman who is involved in peer review.	Michelle will send to Sue Dryden by way of introduction and also to commissioners in East of England and South Yorkshire. Martin to ask lead clinicians whether they have shared it with their management teams.

4	Nephrology support for integrated children's hospitals.	We would like to appoint a new consultant paediatric nephrologist for Nottingham so that NUH provides paediatric nephrology care for Sheffield once Gail has retired. The appointee would be based mainly in Sheffield with support from Nottingham to cover their annual leave etc. The shared care clinics in South Yorkshire could also hopefully be covered by this person. It is hoped that an appointment could be made before Gail retires to enable succession planning. We also need to look at nursing and dietetic support. We are also just starting similar discussions with Leicester to cover Peter Houtman's retirement. The Leicester management team have suggested that discussions should be taken to one table with the commissioners regarding both Sheffield and Leicester. Addenbrookes should be invited to such a meeting as well. Although issues of nephrology support there would have to be interpreted differently, there remain the same issues of providing nephrology support to other specialist children's services which are co-located.	Michelle to organise a meeting to start discussions.
5	Review of national progress	The first meeting of the CRG was held recently which Jane Tizard attended and Martin is hoping to catch up with her shortly. The national service specification for renal has been agreed – NHS England website.	Michelle to send link to Judith for further distribution. Martin will then review and let Michelle know where we think we are at.
6	Education meeting – October	Venue – Stoke Rochford Hall. Theme is to be hypertension with separate disciplinary sessions for doctors, nurses, dietitians and pharmacists. The plan	

		is to hold the steering group meeting on Thursday 3 rd October at 5.30 followed by a meal and overnight stay. Delegates will be encouraged to join us for the meal.	
7	Constitution of steering group	Key people to recruit should include a urologist, psychosocial input, parent/patient, link nurse and link dietitian. It was suggested that we need a “job description” for the parent representative.	To ask for expressions of interest before next meeting. Judith to contact Linda in Glasgow to see if they have a job description.
8	Bringing networks to life	Our progress was discussed in relation to this document. We felt we should focus on 2 pathways initially – a. ESRF, especially transplantation b. Nephrotic syndrome. We have guidelines which need agreeing at the next business meeting. Following this each centre should be benchmarked. There was discussion as to where our accountability lies. Do we need any more documentation or agreement? We need clarity in terms of moving forward. It was felt that transition would be a good care pathway to write/agree. We felt further discussion with SPRUN was required regarding our governance structure and auditing to see how they manage this side of their network. We need to discuss clear audit etc at the autumn meeting.	For discussion at next meeting To discuss with Sue Dryden. ? to set up a pilot audit.
9	Workplan for 2013-2014	a. Pathways	

		b. Clarification on accountability c. Constitution of steering group d. Building of guidelines e. Nephrology support for integrated children's hospitals f. Education days g. Securing financial investment h. Risk register i. Dashboards	All
10.	Date of next meetings	3 rd October 2013 at 5.30 pm. Stoke Rochford Hall 16 th December 2013 at 3.00 pm. NUH	

These minutes accepted as a true record.



30 October 2013