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EMEESY Newsletter

Welcome to the third edition of our newsletter...

For the first time in some years, this year we have decided not to hold a spring nephrouroradiology symposium. We hope to resume next year.

We have set the date for the annual network meeting which will be held on Friday 2nd October, at the Olde Barn Hotel in Marston, near Grantham, where we had our meeting on AKI six years ago. Please put the date in your diaries now! We will return to the theme of CKD but this time with a programme focussed on the nuts and bolts of clinical practice.

It should be a perfect programme for dietitians and nurses and a good opportunity for any who haven't previously been. As before we will make day attendance free for allied healthcare professionals. Please do what you can to support their study leave and travel expenses.

Elsewhere in this newsletter you can read about a parent-initiated patient support group, plans for changes to commissioning of hepatitis B vaccination for children with CKD and some updates on staffing, research and medication.

As ever, please let us have your feedback and if there is anything you would like to see included in a future newsletter, please email Kirsty on kirsty.underwood@nuh.nhs.uk.

Martin Christian, EMEESY Network Lead

KDARS SUPPORT GROUP ARTICLE

KDARS (Kidney Dialysis & Renal Support), this Facebook support group set up by parents of a Nottingham renal patient was covered in a local news story last year. Initially set up to support local families, it has grown so much in 5 years they are now supporting over 1250 people in over 37 countries. Read about the work they do here: www.facebook.com/KDARS4KIDS

HEPATITIS B VACCINATION

In August last year, NHS England transferred responsibility for hepatitis B vaccination from primary care to paediatric renal services for children with CKD meaning that it will no longer be possible to ask GPs to vaccinate children against hepatitis B in preparation for dialysis and transplantation.

We remain committed to delivering care close to home where possible and if there is no way around this directive, we may need to explore whether these children can receive their vaccinations under the responsibility of their local link nephrology team.

We hope to meet up with specialised commissioners in the near future to discuss how to proceed and we will share more details as we have them.

INTRODUCING DR GRACE EHIDAMHEN...

Grace Ehidamhen, known as "Dr Grace" to her patients, is a recently-appointed SPIN paediatrician in EMEESY and writes about her job at Sheffield Children's and her aspirations for service development:

I am the Consultant Paediatrician with a special interest in Nephrology at Sheffield Children's NHS Foundation Trust.

I took over in July 2018 following the retirement of Gail Moss. Being a nephrology SPIN paediatrician at Sheffield Children's Hospital has been a very busy but exciting and fulfilling experience as the workload is vast with a different challenge each day.

The role requires me to provide inpatient and out patient cover for children with renal disease, including inpatient renal support to the general paediatric team and other specialties like PICU, oncology, rheumatology, urology etc.

The nephrology clinical network team at Nottingham provides support with access for advice, on going management and transfer of care to Nottingham when required. I bridge the gap by being on site to assess complex renal patients and provide initial care. This greatly improves patient experience and the need for families to travel to Nottingham for assessment.

In a typical week, I do an average of 3 renal clinics seeing a wide range of patients. Cases range from simple nephrology like CAKUT, microscopic haematuria, PIGN to more complex ones like IgA nephropathy, CKD 1-3, HUS, SLE nephritis, tubulopathies and difficult nephrotic syndrome amongst others. I also have a fortnightly complex UTI and day wetting clinic with two continence specialist nurses.

I have a monthly half-day shared care clinic with Andy Lunn which makes it easy for complex patients like those with CKD 4 to be seen by a tertiary nephrologist locally. Andy also does a monthly whole day clinic at SCH. All renal and urological investigations are done locally apart from renal biopsy.

Recently, I have started a monthly joint nephro-urology clinic with Prof Godbole, Paediatric Urologist, to avoid double hospital attendance for patients with conditions like PUV, nephrolithiasis or CAKUT who are under nephrology and urology. We have a monthly nephro-urology X-ray meeting to review images and discuss cases with the radiologist, urologist, neonatologist and nephrologist in attendance. Both changes have significantly improved the care received by patients with nephro-urological abnormalities.

To ensure patients are safely transitioned to adult care, I do a bimonthly transition clinic with the adult nephrologist, Dr Simon Curran, from Northern General Hospital. Children needing long-term nephrology follow up are transitioned between the ages of 16-18. I aim to start the transition process from 14 years using the Ready, Steady, Go questionnaire.

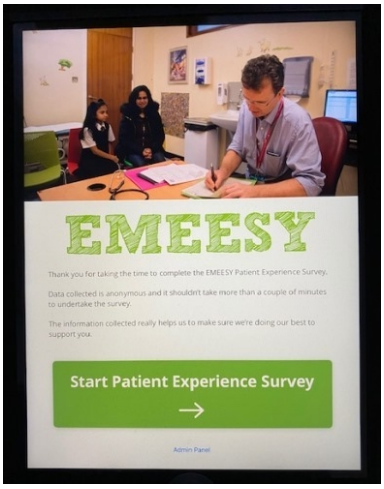
I am super excited as the trust has just employed a part-time renal nurse specialist, Frankie Trench, and renal dietitian, Eleanor Tidswell. This will help develop a proper renal MDT, better establish the service and ensure high quality renal care is delivered at SCH and in the clinical network.

THE EMEESY PATIENT EXPERIENCE SURVEY IS HERE!

After many months of trying, we now have an EMEESY iPad and a customised app built by our website developers Volute.

Over the next few months, when Nottingham specialist nurses attend network clinics, they will bring the iPad with them and try to catch families after appointments for them to fill out this short survey. Demographic questions are about travelling times to their local centre (and travel times to Nottingham) as well as questions about whether they have accessed the information and whole MDT their child needed.

We plan to share individual centre results with the local teams and share composite results generally at the next network meeting. All in the interest of improving standards in patient care.



STAFF CHANGES

Lyn Hopkinson, our social worker, retired in November. We would like to welcome Naseema Hakim who joined us this month.

Claire Hardy, our Hospital Play Specialist left us for pastures new at the end of last year and we hope to be able to make an announcement about her replacement very soon.

Also Ruth Prigg, our dietitian, has moved into a different clinical area. Please bear with Emma holding the fort by herself for now but we hope to appoint a replacement soon.

Across EMEESY we congratulate May Lee on her appointment as a consultant in Derby and offer belated congratulations too to Tina Thekkakara on her appointment in Chesterfield.

PHARMACY NEWS

There is currently a national shortage of azathioprine 25 mg tablets. Cutting tablets in half is not a recommended option so we are advising patients who take 25 mg or 75 mg doses to do asymmetrical dosing to make up the correct dose (e.g. for 75 mg, take 50 mg one day and 100 mg the next day). If you have any queries about this or other drug issues, contact Peter Foxon on peter.foxon@nuh.nhs.uk.

RESEARCH UPDATE

ECUSTEC (Eculizumab in STEC-HUS) is proving harder to recruit to because of a change in HUS demographics but we recruited a second patient this month. Having a Patient Identification Centre set-up to give out information before transfer was critical to the success.

PREDNOS 2 has now completed and we hope there will be some results presented at conferences in the autumn. There are plans afoot for another nephrotic syndrome study, looking at the dose of prednisolone used to treat relapses. More news at the autumn network meeting!

WEBSITE REVAMP

Over the coming months we will be working with our website designers, Volute, to give the website a bit of an upgrade and revamp. The website has been up and running for over 6 years so we feel now is a good time to re-look at it and make some changes.

We held a focus group with some families and young people last last year to get their views on what we can improve and add. One of the main things we learned was how little they knew about the website and its content.

So, as part of this process we will also involve change the EMEESY logo and try to do some wholescale re-branding. In particular we need to look at all sorts of ways we can let families know about the resources we have available.

Keep a look out for the relaunch date!