



BRITISH ASSOCIATION FOR PAEDIATRIC NEPHROLOGY E-NEWS APRIL 2023

Dear colleagues,

I hope everyone is remaining well. After what has felt like a long winter, the days are finally becoming longer than the nights and I feel grateful for the onset of spring and summer ahead! Despite this it's never a quiet week in the NHS and we seem to continue to jump from one predicament to another.

This last month saw industrial action by both our nurses and trainee doctors, the latter being the largest strikes in NHS history. If the next planned doctor strikes are to go ahead, the impact will reverberate across all specialities and services. I want to place on record how much we value our trainee doctor and nursing colleagues and the hard work, energy and value that you bring to our patients and to the speciality as a whole on a daily basis. It is our MDT approach that makes our speciality and community unique. You are the future and as an organisation we aim to make you feel as supported and appreciated as possible. Please do reach out to your supervisors, colleagues and the BAPN if there is more that can be done to support you in your training and careers.

I also wanted to thank and acknowledge our consultant BAPN colleagues for stepping up and supporting our trainee doctors and nurses to participate in industrial action. You have held our services together and enabled the safe and high quality care that our patients deserve. Some of you covered night shifts and others stepped into emergency department vacancies! Some managed inpatient wards and outpatient clinics with reduced support, and others brushed up on their cannulation skills! It is testament to the robustness and resilience of our MDT teams that we can still support each other and navigate through these challenging times safely, but I recognise the strain this puts on everyone. I have no doubt we will continue supporting each other and I hope everyone will plan ahead to take the necessary rest and self-care needed when the opportunity arises during the coming holiday season.

"Do your little bit of good where you are; it's those little bits of good put together that overwhelm the world."

Desmond Tutu

Nabil Melhem *BAPN Secretary*

nabil.melhem@gstt.nhs.uk

BAPN PEOPLE

EXPRESSIONS OF INTEREST SAUGHT FOR ROLE OF PAEDIATRIC REPRESENTATIVE ON THE UKKA CLINICAL PRACTICE GROUP

We are looking for a new BAPN representative to sit on the UKKA Clinical Guideline Committee. This role will provide continuity of paediatric representation on this national committee scrutinising the UKKA guideline activity, but will also provide an opportunity to shape plans for future guidelines including children and young people.

Matko Marlais has been BAPN guideline lead since 2019 and is stepping down, Evgenia Preka will be taking on the role of BAPN guideline lead. We are seeking an additional member to take on Evgenia's previous role as an additional paediatric member of the UKKA committee with

the hope that they would lead on clinical guidelines for the BAPN in the future.

For further information about the role or to express an interest please contact matko.marlais@gosh.nhs.uk by Monday 17th April 2023.

EXPRESSIONS OF INTEREST SAUGHT FOR ROLE OF BAPN COMMUNICATIONS OFFICER

The BAPN executive committee would like to invite brief expressions of interest for the role of Communications Officer, with a handover to commence in April. The post is open to all members. Please could you submit applications by email by Monday 14th April. If more than one submission is received we will arrange a vote.

The position is for a period of 3 years with an optional 1-year extension. The executive committee meets 3 times a year, with opportunities to get involved in other meetings. If you would like more information about the role please contact Lucy Plumb.

lucy.plumb@bristol.ac.uk

Lastly, I would like to take this opportunity to extend a huge thank you from everyone at the BAPN to Lucy for all of the hard work and energy she brought to this role.

GLOBAL HEALTH-NEPHROLOGY FELLOWSHIP OPPORTUNITY IN SRI LANKA

An exciting opportunity for UK/Europe-based trainees who wish to gain experience in nephrology and healthcare in a different [and challenging] health system. The fellowship can be tailored to individual needs and interests with the option to choose either one or a combination of experiences: research, clinical nephrology, service development/quality improvement. Early career consultants who wish to gain global nephrology/global health experience are welcome to apply. 4th/5th year medical student elective opportunities are also available upon request.

UK contact for further information: Dr Maduri Rajay, Birmingham Children's Hospital. Email: m.raja@nhs.net

DISCOUNTED ISN MEMBERSHIP RATE

The UKKA has a special partnership with the International Society of Nephrology that allows UKKA members to access discounted ISN membership rates. If you have already signed up for 2023 let us know at renal@renal.org and we can arrange for the ISN to refund the difference.

For more information on benefits, rates and how to access, click [here](#).

QUALITY IMPROVEMENT AND EDUCATION

EUROPEAN PAEDIATRIC HAEMODIALYSIS SURVEY

The objectives of this survey are to better identify the legal status and organisation of paediatric haemodialysis in each European country and to better understand the human and technical resources available in each centre. We have observed in recent years a decrease in the availability of dialysis machines, permanent HD catheters, a decrease in



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the devices' options allowed for children under 40 kg and an increase in legal concerns. We think we need to strengthen the links between centres across Europe so that we can discuss with the health authorities and build with the manufacturers the devices we need for children.

We would be grateful if the following survey could be filled in by representatives of each centre alongside HD nursing colleagues.

Please access survey [here](#).

SABTO AIDE MEMOIRE

This is a quick reference guide for the safety of deceased donor organs for transplantation, as well as other relevant references. This tool does not replace existing guidance but serves as a rapid reference for clinicians faced with difficult decisions in a time limited situation

<https://www.odt.nhs.uk/transplantation/tools-policies-andguidance/sabto-aide-memoire/>

INFOKID 2.0

The infoKID website has been modernised – see <https://www.infokid.org.uk/>

We need you and our brilliant multi-disciplinary teams in the further developments of the resource that will entail updating all the existing material, adding new resources and maybe new ways of communicating. With KCUK active support at all levels, your infoKID will not only be sustainable but flourishing. We will need a new MDT board to drive the next stage. If anyone is interested in the next stage contact the BAPN Patient Information Lead Yincent Tse at yincenttse@nhs.net

CLINICAL NEWS

POST-STREPTOCOCCAL GLOMERULONEPHRITIS

We are hearing anecdotal reports of higher levels of Post-infectious glomerulonephritis and have received requests for more information from the UK Health Security Agency. This information is not systematically collected as far as I am aware. If anyone has data in this area or is interested in investigating further, please contact nabil.melhem@gstt.nhs.uk

NEW CYSTINOSIS DESIGNATED SERVICES FOR THE UK

Cystinosis has been accepted as a nationally designated service by NHSE, which is wonderful news for our paediatric and adult patients with Cystinosis. The service is supported by the patient charity Cystinosis Foundation UK. The 3 designated centres are combined paediatric and adult units in Birmingham, Guys/Evelina and Manchester. These units will be providing MDT clinics in a 'Hub-and-spoke' model with more distant patients being seen annually in a one stop clinic.

The service will supplement and not duplicate the care already delivered by local teams for these patients across all age ranges, with

particular emphasis on peer support for this rare condition and transition to adult services.

The aim of this service is not to take over the care of patients with cystinosis from tertiary centres, but to work alongside them in providing patients with harmonised care and equitable access to holistic MDT services for all patients with Cystinosis. Services will provide patients with peer support and facilitate effective transition to adult services as each unit is working closely with their adult counterpart. There is close liaison with RaDaR to ensure data is captured effectively for all patients with cystinosis across England. Devolved countries can use their existing referral pathways to units in England if families wish to be seen in this service.

Designated centres may contact nephrology units directly to highlight what can be offered, alternatively do contact a centre close to you if you would like more information on the services offered. Watch this space for more information.

HOME DIALYSIS UTILITY BILL REIMBURSEMENT

NHS England's Women and Children's Programme of Care, responsible for paediatric specialised services, has made changes to the paediatric renal services specification.

The change now includes the requirement for all NHS Hospital Trusts to reimburse households for additional direct utility costs associated with paediatric haemodialysis or peritoneal dialysis received in the home.

This change will hopefully make it easier for our home dialysis families to receive the support they are entitled to. Please share with service managers in your departments.

The UKKA kidney patient safety committee with BAPN representation has produced national [guidance](#) on home dialysis utility costs and home adaption reimbursement. There is also a very useful [reimbursement calculator](#) for water and electricity based on the dialysis prescription. The recommendations outline provider responsibilities (NHS Trusts/Health Boards) costs of home adaptation and reimbursement of utility costs for home dialysis.



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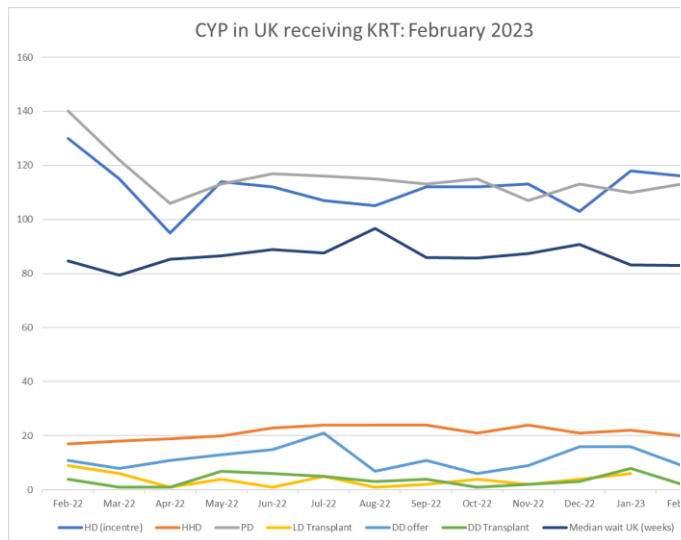
DIALYSIS AND TRANSPLANT NUMBERS

In 2021 we reported a rise in the number of CYP receiving dialysis in the UK to approximately 40% above a previous steady baseline (285, compared with 207 in 2019). Dialysis numbers stabilized in 2022 and 2023, but have not fallen to previous baselines. The median waiting time increased in 2022 but has now stabilised in the last 6 months. Deceased donor transplants remain low but steady in 2022/2023.



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We are continuing to monitor this carefully via the paediatric subgroup of the NHSBT Kidney Advisory Group (KAGPSG). Thank you to everyone who has contributed to collecting national data.



LATEST UKKA COVID ADVICE

The statement linked below provides an updated summary of UKKA's recommendations for the care of people with kidney disease in the current phase of COVID-19.

[Read statement](#)

NICE DRAFT GUIDANCE ON THERAPEUTICS FOR PEOPLE WITH COVID-19

Thank you to everyone who contributed to our response to the NICE draft guidance on Therapeutics for people with COVID-19. With special thanks to our collaborating scientists and expert patients who provided rigorous data and real patient perspective to the NICE committee, our combined efforts have resulted in a policy change.

Initial draft guidance issued in November had only recommended Paxlovid for the treatment of adult outpatients with COVID. This left many people with kidney disease without optimal treatments. Following feedback from across the kidney community, NICE are now recommending that Sotrovimab remains available to people who cannot take Paxlovid. The final recommendation is that Paxlovid (for adults) and Sotrovimab (for all of 12 years or over) are available to treat people who test positive for the virus in the community and that additional Tocilizumab (for adults) can be used for people who are admitted to hospital and require additional oxygen. This will now provide further protection to people with late kidney disease, those with transplants, or those on dialysis.

Final publication of the guidance is expected around 29th March 2023.

MELODY STUDY PRE-PRINT

Please see below a pre-print of antibody prevalence after 3 or more COVID-19 vaccine doses in 23,000 immunosuppressed individuals: a cross-sectional study from MELODY.

[Antibody prevalence after 3 or more COVID-19 vaccine doses in 23,000 immunosuppressed individuals: a cross-sectional study from MELODY | medRxiv](#)

RESEARCH NEWS

GRANTS NOW AVAILABLE FOR UKKW

There are now a limited amount of grants available to cover the cost of attending UKKW. Priority will be given to those who have presented or plan to present at UK Kidney Week

[Click here](#) to find out if you're eligible and for info on how to apply.

Grant applications close on 1st May 2023

SAVE THE DATE - UKKA AKI SPECIAL INTEREST GROUP

The UKKA AKI SIG are planning to hold a national AKI summit meeting on Tuesday 26th September 2023 in Birmingham. More details and programme to come soon. It would be great to have paediatric representation on this too.

Email ukka@ukkidney.org with questions.

A PHASE 2 OPEN LABEL PILOT STUDY TO EVALUATE THE SAFETY AND EFFICACY OF SUBCUTANEOUSLY ADMINISTERED ELX-02 IN PATIENTS WITH ALPORT SYNDROME WITH COL4A5 AND COL4A3/4 NONSENSE MUTATION

Please see attached a patient recruitment letter from Professor Detlef Bockenhauer outlining recruitment for a new trial.

This is a commercial trial of an amino glycoside derivative that facilitates "read-through" of nonsense mutations. It is a really exciting trial, but because only specific genetic mutations are eligible, recruitment is challenging. Please see the attached letter so that eligible patients across the whole of the UK can have a chance to participate. They will have to travel to London, but the trial will provide travel expenses.



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SURVEY ON TARGET BP RANGES IN CHILDREN



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The UK Kidney Research Consortium (UKKRC) cardio-renal clinical study group is developing a pan-UK randomised control trial of target BP ranges in adult HD patients. They have approached us to see if a national RCT and clinical practice guideline for the management of BP in children and young people on HD may be beneficial/desirable.

Manish Sinha and Douglas Stewart have set up a quick survey to assess practice across all the tertiary centres and gauge interest in this area.

Please find attached the link for the survey here:

<https://forms.office.com/r/NgiDQ90qy0>

TRAINEES AND TRAINING

GRID TRAINING DAYS

The next GRID Training Days will be hosted by Glasgow on the 3rd & 4th May 2023. All GRID and SPIN trainees are invited to attend. Any other trainees who are interested in attending please email me to express your interest.

ashish.patel3@nhs.net

KIDNEY SCHOOL

Kidney School is a virtual educational meeting for all trainees with GRID or SPIN interest where we discuss clinical scenarios and the latest scientific literature. The programme is restarting from February and if you would like to attend, please email me and I will include you on the mailing list.

ashish.patel3@nhs.net

BUDDY SCHEME - INVITE TO CONSULTANTS

We currently have a large cohort of trainees with 6 trainees due to CCT in 2023. I am interested to see if there is scope to extend our buddy scheme to support these newly appointed consultants and build networks. If you would be willing to mentor a finishing GRID trainee, please get in touch.

Ash Patel, BAPN GRID Trainee Representative, Birmingham

ashish.patel3@nhs.net

SPIN NEPHROLOGY CURRICULUM

The updated SPIN Nephrology curriculum is available on the RCPCH website;

<https://www.rcpch.ac.uk/resources/special-interest-spin-module-application-guidance>

Questions and feedback on curriculum content can be sent to Dr Hannah Cottis: hannahcottis@nhs.net.

FUTURE EVENTS

EVELINA PAEDIATRIC NEPHROLOGY WEBINAR SERIES: MANAGING CHILDREN WITH RENAL CONDITIONS

We are pleased to announce the continuation of the Paediatric Nephrology webinar series.

Programme (subject to change)

12.04.23 – What to consider in the child with a kidney transplant. Grainne Walsh, Transplant ANNP

10.05.23 – Polycystic Kidney disease-what's new? Dr Manish Sinha

14.06.23 – The multi-disciplinary approach to the child with cystinosis. Dr Nabil Melhem

12.07.23 - What do you do with the child with recurrent UTI's? Dr Jo Clothier

Open to GPs, General Paediatric Consultants, Junior Doctors and Nursing staff - both hospital and community based.

Starting Wednesday 14th September 2022, 12.00-13.00, virtual event, £10.00

<https://paediatricnephrologywebinarseries.eventbrite.co.uk>

GOSH NEPHRO-UROLOGY COURSE – 24TH-28TH APRIL

Please remember to send your availability to present your interesting biopsies, ultrasounds and imaging to stephen.marks@gosh.nhs.uk and zainab.arslan@gosh.nhs.uk for the Continuing Education Programme in Nephrology Week 2023 from Monday 24 to Friday 28 April 2023 (registration from 0900h with morning sessions 0930h to 1300h and afternoon sessions 1400h to 1730h)

A five-day course consisting of hybrid lectures on Monday morning, Thursday and Friday and for those attending the conference in London, there will be additional face-to-face only workshops on Tuesday and Wednesday for the first time since the COVID-19 pandemic.

The lectures will take place in the Zayed Centre for Research into Rare Disease in Children (part of Great Ormond Street Hospital for Children NHS Foundation Trust) with live streaming as Zoom webinar for those unable to attend London.

This course aims to increase your knowledge and understanding of paediatric nephrology using different symposiums and workshops.

The course is suitable for paediatric nephrologists, including those training and members of the multi-disciplinary team, paediatricians with an interest in nephrology and general paediatricians

¹Lectures in Ryan Connolly Seminar Room, Zayed Centre for Research into Rare Disease in Children (part of Great Ormond Street Hospital for Children NHS Foundation Trust) at 20 Guilford Street, London, WC1N 1DZ on Monday morning, Thursday and Friday (all day)

²Workshops in separate venue on Tuesday and Wednesday (all day): all face-to-face attendees rotate through both workshops during two morning sessions (0930h to 1100h and 1130h to 1300h) and two afternoon sessions (1400h to 1530h and 1600h to 1730h)

Course Directors: Prof Stephen Marks and Dr Zainab Arslan



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Please contact: stephen.marks@gosh.nhs.uk,
zainab.arslan@gosh.nhs.uk and events.gla@gosh.nhs.uk

Please see our [registration](#) page for more event details and prices.



Nephro-Urology
course - Programme I



Nephro-Urology
course FINAL.pdf

PAEDIATRIC URODYNAMICS COURSE – 11TH-12TH MAY 2023

Tickets for the Evelina 2023 Urodynamics course are now on sale. The course will be face to face and will take place on Thursday 11th and Friday 12th May 2023.

Tickets for Nurses/ AHP are priced at £85.00 and tickets for Doctors are priced at £155.00. Tickets for each day are sold separately, you can choose to attend on one or both dates.

For more information about the course and to book your place please follow the link below:

<https://paediatricurodynamicscourse2023.eventbrite.co.uk>

RCPCH CONFERENCE 23-25TH MAY 2023

The RCPCH Conference returns to Glasgow from 23 to 25 May, and we'd love to see you there.

The theme will be 'Child health in a changing world' - more relevant than ever as we navigate challenges and opportunities in paediatrics.

More information [here](#).

UK KIDNEY WEEK 2023 5TH – 7TH JUNE 2023

Registration for UK Kidney Week 2023 is now open with an early bird discount until March.

UK Kidney Week will take place from 5th - 7th June 2023 at the International Convention Centre Wales.

Register [here](#) now

INVITATION AND CALL FOR ABSTRACTS - 51TH ANNUAL MEETING OF THE EUROPEAN WORKING GROUP ON PSYCHOSOCIAL ASPECTS OF CHILDREN WITH CHRONIC RENAL FAILURE (EWOPA) – 8TH-10TH JUNE 2023

It is our great pleasure to invite you to Leuven in June for the 51th EWOPA meeting!

EWOPA is a multidisciplinary group interested in the psychosocial care of children and adolescents with chronic kidney disease (CKD). Childhood CKD is a rare condition at the heart of the European Rare Kidney Disease Reference Network (ERKNet). The EWOPA meeting is fully aligned with ERKNet's mission to promote interdisciplinary care and research focused on patients' needs.

The conference will be held onsite at the University Hospital Leuven from 8 to 10 June 2023.

We invite all stakeholders caring for children with CKD to participate, both with scientific reports and with presentations of activities, interventions and experiences in everyday clinical practice, with focus on psychosocial issues and multidisciplinary care of children and adolescents with CKD.

For registration and submission of abstracts, please visit our website: www.ewopa2023.org

FIRST INTERNATIONAL CONFERENCE OF CRITICAL CARE NEPHROLOGY IN CHILDREN - 27TH - 29TH JULY 2023

REGISTRATION AND ABSTRACT SUBMISSION NOW OPEN

On behalf of King's College Hospital London, Cincinnati Children's Hospital and the European Society of Pediatric and Neonatal Intensive Care (ESPNIC), we cordially invite you to take part in the First International Conference of Critical Care Nephrology in Children on 27th - 29th July 2023.

The conference venue is in the heart of Westminster at the Queen Elizabeth II Centre.

Within recent years, significant advancements have been made in the application of Renal Replacement Therapies in the management of Acute Kidney Injury in the paediatric and neonatal populations. Many of these innovations will be presented and discussed at the conference along with inclusion of pre-conference workshops in providing a unique and valuable hands-on experience.

More information and registration [here](#).

ESPN CONFERENCE VILNIUS, LITHUANIA 28TH SEPTEMBER TO 1ST OCTOBER 2023

The 55th Annual Meeting of the European Society for Pediatric Nephrology (ESPN) will this year be held in Vilnius, Lithuania on 28th September to 1st October 2023.

Abstract submission deadline is 2nd April 2023 23:59.

More information [here](#).