



## BRITISH ASSOCIATION FOR PAEDIATRIC NEPHROLOGY E-NEWS SUMMER 2022

Dear colleagues,

The latest extreme weather conditions have brought into sharp focus the reality of climate change impacts and heat vulnerability in the UK. I believe I speak for all when I say that we need to do all in our power to advocate for a more sustainable future for our patients and society. Without change, heat-related deaths are expected to rise from 1,600 last year to 7,000 each year by the 2050s according to the RCPCH. As an organisation we will be making representations on our position about the urgency needed to tackle climate change now.

The General Medical Council's annual national training survey was also released this month and reveals a continuing worsening trend related to workload and burnout. Amongst paediatricians, 11% of trainers are saying they are burnt out, which is a rise of 3% compared to last year. 15% of paediatric trainees say they are burnt out, a rise of 4% from last year. I hope that everyone remembers to be kind to themselves this summer, and a reminder to look out for our fellow colleagues, trainees and other MDT members who may be struggling. It is with a huge amount of pride that I can say in the Paediatric Nephrology family, I truly believe we go that extra mile for each other and I have little doubt that in challenging times, we can continue to be there for one another. As summer is upon us, I hope everyone is able to enjoy some very well deserved rest and relaxation with friends and family.

Nabil Melhem *BAPN Secretary*  
[nabil.melhem@gstt.nhs.uk](mailto:nabil.melhem@gstt.nhs.uk)

### BAPN PEOPLE

#### BAPN LAY REPRESENTATION

Ms Kamal Dhese is now stepping from this role, having been a valued member of the team, bringing patient perspectives to the forefront of everything we are doing. I would be grateful if members could look within their teams for parents or carers who would be interested to join our team.

#### EOI – BAPN SPIN REPRESENTATIVE

From September Adamu Sambo will be stepping down from his role as SPIN representative on the BAPN executive committee. I'd like to extend our deepest gratitude and for Adamu's work and contributions and we wish him well.

We are looking for expressions of interest for a new SPIN representative. Please can anyone interested email me at [nabil.melhem@gstt.nhs.uk](mailto:nabil.melhem@gstt.nhs.uk) by 20<sup>th</sup> September 2022.

### NEWLY APPOINTED CONSULTANTS

Huge congratulations to our newly appointed consultants in the BAPN family. Faidra Veligratli and Iona Madden have been appointed consultants at Great Ormond Street Hospital, London. Gajen Sellathurai has been appointed to a Locum consultant post in Evelina London Children's Hospital and Maddy Raja has been appointed to a Locum consultant post at Birmingham Women's and Children's hospital.

### QUALITY IMPROVEMENT AND EDUCATION

#### EDUCATIONAL VIDEOS

Shazia Adalat from the Evelina London has secured funding for 12, 3-minute long animated educational videos for explaining renal conditions to children. We hope these will be a really useful resource for patient education, complementary to the resources on InfoKID and would be keen to recruit interested individuals across the paediatric nephrology community (patients and professionals) who would be interested in collaborating or having input into these, so that these become a resource for every centre to be able to use and promote. Please email [Shazia.adalat@gstt.nhs.uk](mailto:Shazia.adalat@gstt.nhs.uk) if you wish to be part of this.

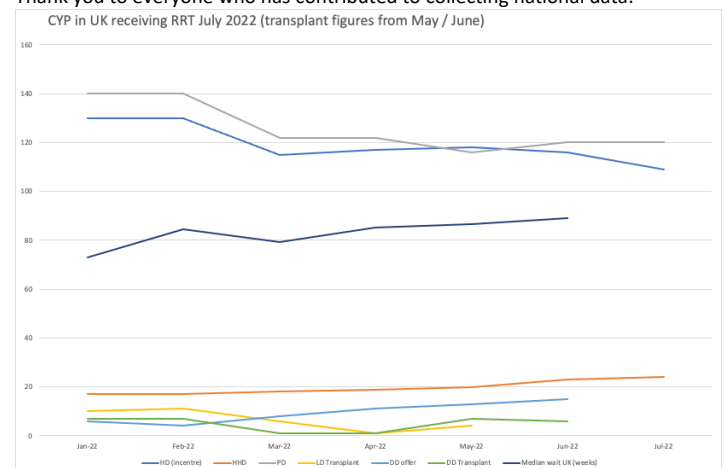
#### PATIENTS KNOW BEST

The national patient-facing system linked to the Renal Registry is being changed from PatientView to the [Patients Know Best](#) personal health records platform. Work on this is ongoing. Please see the following link for more information about how this changeover will work: [PatientView → Patients Know Best | The UK Kidney Association](#). The switch to PKB is expected to be complete by the end of 2022 and PatientView maintenance will then cease. Please can we all start to share this information with our families currently using PatientView to help them prepare.

### CLINICAL NEWS

#### 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). In February 2022 to July 2022, numbers have fallen slightly, however we are still seeing an increase in deceased donor waiting list times. 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.



BAPN e-News is sent electronically to members on a 1-2 monthly basis. Please send in your unit news to: [BAPNsecretary@renal.org](mailto:BAPNsecretary@renal.org)



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### ALTEPLASE 2MG SUPPLY ISSUE

There is an ongoing supply shortage of Alteplase 2mg which is used for paediatric haemodialysis central venous access preservation. Shortages are due to last until at least 2024. As well as representations on the UKKA Kidney Patient Safety Committee to highlight the safety impact this will have on our patients, Martin Christian has contacted each centre to ascertain contingency plans. These range from changing to Taurlock, using in-house frozen Alteplase supplies and importing Alteplase from abroad, however these are not secure lines of procurement. We are asking for a nationally coordinated response from the DHSC medicines supply team to help us to address this issue.

### UPDATE FOR COVID MANAGEMENT ON DIALYSIS

The [latest UKKA recommendations](#) on measures to prevent transmission of COVID-19 in haemodialysis settings are available here. This document is now closed for comment but future updates will be posted here in future e-News editions.

### MILD-MODERATE COVID TREATMENT IN COMMUNITY - SOTROVIMAB

Sotrovimab is a MAB therapy that is being advised by NHS England and NHS Improvement in those with COVID, 12 years of age and older and >40kg in high risk groups, which includes some of our patient groups. It is for use in mild – moderate COVID in the community to prevent hospitalisation and for those with COVID symptoms severe enough to need hospitalisation. NHS England will be contacting people they think are eligible. The treatment has been shown to be safe and effective in over 18 year olds.

The MHRA information is available online  
[Summary of Product Characteristics for Xevudy - GOV.UK \(www.gov.uk\)](#)

[MHRA approves Xevudy \(sotrovimab\), a COVID-19 treatment found to cut hospitalisation and death by 79% - GOV.UK \(www.gov.uk\)](#)

Currently we would advise an individual risk / benefit discussion with any eligible patients as the incidence of serious illness with COVID is much lower in children and young people.

### COVID VACCINATION

General information about the vaccine is available on the BAPN and RCPCH websites. The Pfizer vaccine is licensed for children and young people 5 years of age and older. RCPCH advice is online.  
<https://www.rcpch.ac.uk/resources/coronavirus-vaccination-programme-statement>

Further information is to be included in the new chapter of the Green Book <https://www.gov.uk/government/publications/covid-19-the-green-book-chapter-14a>

We have also updated our guidance and will continue to review this regularly. Links to all of our guidance are on the website.  
<https://renal.org/health-professionals/covid-19/bapn-resources>

### RESEARCH NEWS

#### NAMED AWARDS - KIDNEY RESEARCH UK

KRUK are now inviting applications for [Named awards - Kidney Research UK](#). These awards are in addition to their grants rounds and highlight their commitment to building a stronger and broader research community. All awards will be made in line with KRUK's research strategy and all applicants are advised to consider this carefully prior to submission.

#### QUESTIONNAIRE ON SUPPORTIVE CARE IN ESKD

Please see attached a questionnaire from the UKKA Paediatric Supportive Care Working group about supportive care in paediatric end stage kidney disease. We are asking for responses from every unit. Several units have responded but we are still waiting for a more complete national picture. Please send replies to:  
[ben.reynolds@ggc.scot.nhs.uk](mailto:ben.reynolds@ggc.scot.nhs.uk)



#### PHASE 3 TRIAL OF NEDOSIRAN IN PH1 AND PH2

GOSH has just opened recruitment for two industry phase 3 trials of Nedosiran for children with PH1 and PH2. The time windows to recruit are short (estimated completion date October 2021) as the numbers are small and it's an international study.

If you have a patient with PH1 or PH2 who may be eligible please contact Wes Hayes [Wesley.Hayes@gosh.nhs.uk](mailto:Wesley.Hayes@gosh.nhs.uk) for more details. Travel and accommodation expenses are covered for participants and their families.

#### BPSU CONSERVATIVE CARE IN END-STAGE CKD

A BPSU study looking at children who reach end-stage kidney disease for whom a decision is made not to pursue long-term kidney replacement therapy is running until September 2022. Please report any children <16 years who meet the following three criteria:

1. Suspected or confirmed chronic kidney disease (abnormalities of structure or function which are expected to be long term).
2. Children who have reached end-stage kidney disease on or after Sept 1, 2020. For infants (<12 months), this is defined as 2 or more creatinine values of 120 micromol/L or more. For anyone else, this is an estimated GFR of <15.
3. A decision has been made in their best interests not to pursue long-term kidney replacement therapies. *If the child had a brief period/trial of <90 days before stopping, they can also be reported.*

For further information, governance approvals and public information, see <https://www.rcpch.ac.uk/work-we-do/bpsu/study-conservative-care-end-stage-kidney-disease>



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If you are unsure whether a case meets criteria or if they have already been reported, please get in touch with Lucy at [lucy.plumb@nhs.net](mailto:lucy.plumb@nhs.net).

### TRAINEES AND TRAINING

#### 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>

The training services team will set a date for completion of the old curriculum, and trainees completing beyond that date will be recommended to move over and re-tag to the new curriculum. All new applicants will be provided with the new curriculum on their eportfolio. Questions and feedback on curriculum content can be sent to Dr Adamu Sambo [Adamu.sambo@nhs.net](mailto:Adamu.sambo@nhs.net).

#### KIDNEY SCHOOL

Kidney School is a virtual peer group for all trainees with GRID or SPIN interest. The feedback is very good and it is a much appreciated resource.

If you are a trainee with GRID/SPIN interest and would like more info on how to access this or some of the other educational and social events organised by the trainees contact the trainee rep Ashish Patel (email: [ashish.patel3@nhs.net](mailto:ashish.patel3@nhs.net)).

### FUTURE EVENTS

#### 19<sup>TH</sup> IPNA CONGRESS, CALGARY 7-11<sup>TH</sup> SEPTEMBER 2022

The 19<sup>th</sup> IPNA congress is due to be held this year in Calgary, Canada from 7<sup>th</sup> until 11<sup>th</sup> September.

More information can be found here

<https://espn2022.org/>

#### KING'S COLLEGE LONDON - OPTIMISING KIDNEY UTILISATION COURSE 7<sup>TH</sup> OCTOBER 2022

Transplant colleagues from Guy's & St Thomas' are running the second King's College London Optimising Kidney Utilisation Course in October.

The course is 100% virtual, and is aimed at senior nephrology trainees, senior transplant surgical trainees, and senior nurses with an interest in UK deceased donor kidney transplantation and consultant colleagues looking for an update on recent advances.

The aims of the course are to help attendees to:

- Better understand the context of UK deceased donor kidney transplantation

- Improve knowledge around national offering schemes
- Be more informed on the evidence-base for the use of increased risk organs
- Develop a framework for approaching complex organ offering scenarios

Programme and course flyer is attached in the link below:

<https://www.kcl.ac.uk/short-courses/optimising-kidney-utilisation-2022>