



BRITISH ASSOCIATION FOR PAEDIATRIC NEPHROLOGY E-NEWS JANUARY 2023

Dear colleagues,

Welcome everyone to 2023! I wish you all a very happy and wonderful New Year with family, friends and colleagues. From resolutions, to bucket lists and from work to-do lists to that paper that just won't write itself... I wish you every success in all you set out to achieve at home and at work.

The turn of the year always feels like a good time to reflect on the year that has passed whilst looking forward to the future ahead. I am really proud of what our community has achieved in the last year. We came out of yet another COVID wave and lock-downs at the end of last year, we said goodbye to much loved colleagues, we welcomed new trainees and BAPN members, we pulled together again to meet in another successful virtual conference, our QI activity continues unabated, we were fantastically represented in UK kidney week, we endured heat waves and cold snaps, train strikes and relentless work pressures to give the best care possible to our patients. Amongst all of this our research output has been as impressive as ever. It was a privilege to read through countless high quality abstracts submitted to the next BAPN winter meeting as evidence of an energised and vibrant group of paediatric nephrologists, nurses and trainees and I feel optimistic about our year ahead.

We are very excited about the upcoming BAPN 50th anniversary winter meeting this month alongside our PNNG colleagues for the first time. It will be wonderful to all gather for the first time in several years, celebrating our history and sharing our work. Please do take the opportunity to [register](#) and share registration details amongst colleagues in your department.

"Every time you tear a leaf off a calendar, you present a new place for new ideas". Charles Kettering

Nabil Melhem *BAPN Secretary*

nabil.melhem@gstt.nhs.uk

BAPN 50TH ANNIVERSARY / PNNG 25TH ANNIVERSARY MEETING – 26/27TH JANUARY IN LEEDS – REGISTRATION OPENED

Our landmark 50th anniversary BAPN winter meeting will be held on the 26th and 27th of January in Leeds. This will also be our first joint meeting with our nursing PNNG colleagues, who will also be marking their 25th anniversary. We are putting together a great programme of speakers and topics, and we will also be joined by patient advocate Maddy Warren with her acclaimed photo exhibition [Survivors: Life Unfiltered](#). We are also delighted to welcome retired colleagues this year to mark this special occasion.

Please do register ASAP for the meeting and don't forget to select your dinner menu choices in your confirmation email. We have a wonderful dinner and menu planned at the Tetley contemporary art gallery in Leeds. Dinner options will be on a first come first served basis. We look forward to welcoming you all there.

Register for your place [here](#)

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

BAPN PEOPLE

BAPN SURGICAL CHALLENGES MEETING

Attached is a lovely photo from the Surgical challenges meeting in November. It was great to have every centre represented in what I'm told was a very interesting and lively meeting!



BAPN NURSE REPRESENTATION ON EXECUTIVE COMMITTEE – WELCOME ROY CONNELL

We are delighted to welcome and announce the appointment of Roy Connell as the first nurse onto the BAPN executive committee. Roy from the Nottingham team is the chair an active member of the Paediatric Nephrology Nursing Group and brings with him a wealth of experience and knowledge to our group. He is a wonderful voice for our nursing colleagues and we all look forward to working closely with Roy in the coming year.

SUBMIT AN ABSTRACT FOR UK KIDNEY WEEK 2023 5TH - 7TH JUNE 2023

Abstract submission is now open until 24th January 2023. We look forward to incorporating the latest research, quality improvement and case reports into the programme. Abstracts are invited from all members of the multi-professional team and must be uploaded via the [submission portal](#)

Registration opens in late January with an early bird discount until March.

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

UK DIAGNOSTIC & INTERVENTION NEPHROLOGY (UK- DIN) SPECIALTY INTEREST GROUP (SIG) – PAEDIATRIC REPRESENTATION

Interventional nephrology (IN) is a new and emerging subspecialty of Nephrology. Traditionally, mixtures of interventional radiologists,



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nephrologists and surgeons have performed the interventional procedures in nephrology.

The aim of the UK-DIN SIG is to advise on an Interventional Nephrology training and develop a framework for educational progression to support this professional development through sub-specialty training in IN for the multi-professional team.

It would be great to have paediatric representation in this group. If anyone is interested, please get in contact to discuss further

Nabil.melhem@gstt.nhs.uk



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RCPCH INVITED REVIEWS SERVICE (IRS) CALL FOR CLINICAL REVIEWERS

Following a pause in service, the RCPCH IRS is almost ready to resume and start undertaking reviews once again. Paediatric nephrology specialty is currently underrepresented and the RCPCH would like to offer interested members of the BAPN an opportunity to apply to join the pool of invited reviewers so that the specialty is represented should a review in this specialty arise.

To provide some background and context, the RCPCH Invited Reviews Programme was developed in 2012 as a valuable quality assurance and improvement tool, utilising expert independent peer review to help assure patient safety, address issues of concern at an early stage and improve the quality of care in children and young people's health services.

Interested individuals can read more about the role of an RCPCH invited reviewer, and apply, by visiting [here](#).

QUALITY IMPROVEMENT AND EDUCATION

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-and-guidance/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 Vincent Tse at vincenttse@nhs.net

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. 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 will complete by late February 2022 and PatientView maintenance will then cease. Please liaise with colleagues to ensure that your department is on track and share this information with our families currently using PatientView to help them prepare.

CLINICAL NEWS

HOME DIALYSIS UTILITY BILL REIMBURSEMENT

The 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 adaptation 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.



service framework
update home therap

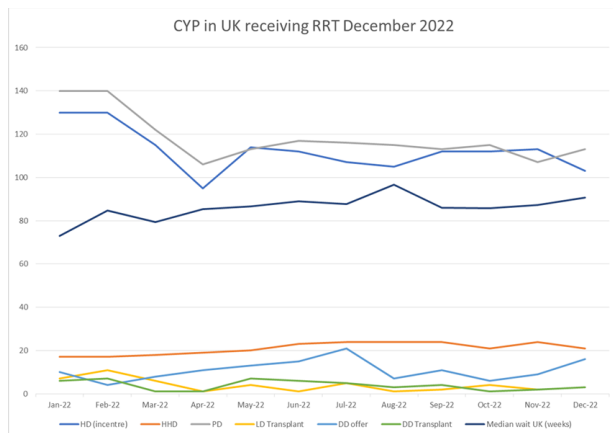
DIALYSIS AND TRANSPLANT NUMBERS



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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 have stabilized in 2022, but not fallen to previous baselines. We have seen a steady increase in the median deceased donor list waiting times over the course of the year.

There has been an increase in deceased donor kidney offers over the last few months, however this has not yet translated to more deceased donor transplants. The median wait time has remained stable this month. We are continuing to monitor this carefully via the paediatric subgroup of the NHSBT Kidney Advisory Group (KAGPSG) and are hoping more offers will translate to more transplants. Thank you to everyone who has contributed to collecting national data.



LATEST UKKA COVID ADVICE – DECEMBER 2022

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](#)

RESEARCH NEWS

HARMONISATION OF THE MANAGEMENT OF PAEDIATRIC GLOMERULAR DISEASE

As a key step towards achieving a perpetual platform trial for glomerulonephritis - Louise Oni & Martin Christian are looking for members to undertake the following project: 'Harmonisation of the management of paediatric glomerular disease'

Commitment:

- 1 x Virtual pre-meeting in mid Feb (date TBC)
- 1 x Face to face meeting in Liverpool city centre Thurs 16th March from 2pm to 17th March at 4pm with overnight accommodation

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

10 x monthly virtual meetings (dates TBC)

Ideally:

- One UK paediatric nephrologist from each BAPN centre
 - One UK paediatric pathologist
 - One UK renal paediatric pharmacist
 - One UK adult nephrologist
 - One UK lay member
- Reasonable expenses will be covered

To submit an expression of interest please complete the hyperlinked form <https://forms.gle/Dd5Q57B6pwycM4b79> before Friday 3rd Feb 2023



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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EVALUATION OF UK PAEDIATRIC NEPHROLOGY TEAMS' UNDERSTANDING, EXPERIENCE AND PERCEPTIONS OF ORAL HEALTH OUTCOMES AND ACCESSIBILITY TO DENTAL CARE

This is a UK-wide survey being led by the Newcastle University School of Dental Sciences and the Great North Children's Hospital. Favourable ethical approval has been obtained from Newcastle University (24983/2022).

The aim of the survey is to evaluate paediatric nephrology consultants', registrars' and specialist nurses' experience of adverse oral health outcomes in Children and Young People (CYP) with kidney disease. Furthermore, it will evaluate your perceptions of how readily you feel your patients can access dental care and how confident you feel at



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recognising and escalating relevant oral health concerns in your patient group.

We estimate that the survey will take no more than 10 minutes to complete. Participation is voluntary and data will be stored securely on Newcastle upon Tyne Hospitals Trust and Newcastle University servers.

Should you require any further information or have any questions, please contact the project team via email (Christopher.Wallace3@nhs.net or Greig.Taylor@newcastle.ac.uk)

Survey link [here](#).

SURVEY ON TARGET BP RANGES IN CHILDREN

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/NgjDQ90qy0>

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



TRAINEES AND TRAINING

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. It is a valuable resource for our trainees and the programme will be restarting from September.

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

PRIORITIES FOR LONG COVID SERVICES, CARE AND RESEARCH – 31ST JANUARY 2023

This conference will discuss the future for long COVID research, services, and care. It will be an opportunity to assess Long COVID: the NHS plan for improving long COVID services and how its ambitions for improving access to services, patient experience and outcomes for patients can be achieved.

Further sessions examine priorities for research and improving understanding of long COVID, looking at implementing the latest developments in research to improve services, and the long-term health implications of long COVID.

More information and booking can be found [here](#).

Dear colleagues and friends,

ADVANCES IN PAEDIATRIC DIALYSIS – 2ND-3RD FEBRUARY 2023

We look forward to welcoming you to our CME event on 'Advances in Dialysis' on 2 and 3 Feb 2023. Given the success of a virtual conference over the past years, we have decided to continue with this as a virtual meeting. The course will be free to all dialysis nurses, technicians, allied health professionals and those from low and middle income countries.

A program and link for registration information is included.



Advances in Dialysis



Adv in Dialysis

EVELINA PAEDIATRIC NEPHROLOGY WEBINAR SERIES: MANAGING CHILDREN WITH RENAL CONDITIONS

We are pleased to announce the next Paediatric Nephrology webinar series is due to start again from next week.

Proposed programme (subject to change)

11.01.23 – Investigating and Managing enuresis. Dr Jo Clothier

07.02.23 (TUES) – Investigating renal cysts and managing the child with cystic kidney disease. Dr Nick Ware



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08.03.23 – Investigating and managing children with kidney stones. Mr Arash Taghizadeh

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 - TBC

12.07.23 - TBC

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>

PAEDIATRIC URODYNAMICS COURSE – 11/12TH 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 - ABSTRACT SUBMISSIONS INVITED

The RCPCH Conference Organising Committee is pleased to invite abstract submissions for the 2023 Conference, which will take place from 23 to 25 May in Glasgow.

The deadline to submit your abstract is Monday 6 February, 23:59. Submit abstracts [here](#).

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.