

In Touch

Information from the National Kidney Federation. Supporting kidney patients, their friends & family.

Welcome to the December 2021 In Touch newsletter. Please feel free to share with your friends, family and colleagues. If you are receiving this newsletter from someone else and not the NKF, you can contact us and request to be added to our mailing list.

In this Issue

Action Point

- 02 Reflecting on 2021
- 02 NKF Peer Support Services
- 03 APPKG Update
- 04 Northamptonshire Kidney Patient Association
- 05 New Editor Required for Kidney Life Magazine
- 05 Help Raise Awareness of Anemia of CKD

News

- 06 Covid-19 Updates
- 07 Melody Research Study
- 07 NKF Facemasks and Lanyards Available
- 08 Patients Know Best
- 09 The New Chiltern Kidney Centre

Patient Participation Opportunities

- 10 Hyperkalaemia - Patient Filming Project

NKF Helpline

- 11 The Transplant Phone Call: What to expect

NKF Fundraising

- 12 A Big Thank You To Our Fundraisers

If you have an article that you would like sharing in the next newsletter, please forward to Sharney Warren at sharney@kidney.org.uk by 10th January 2022.



Reflecting on 2021

On behalf of the NKF I would like to take the opportunity to thank each and every one of you for your support during another very difficult year for everyone. We hoped COVID would have disappeared by now, but it is still very prominent in all of our lives.

The NKF has had a very productive year, we began our five year strategy, worked with the national groups for COVID, commenced our increasing home dialysis campaign, set up the national peer support service, increased our staffing levels including the helpline staff and reformed the All Party Parliamentary Kidney Group, to name a few achievements.

2022 will be another busy year for the NKF, we will continue to campaign for and support you all with every day that passes.

I wish you and your family a happy and healthy Christmas and New Year.

Best Wishes,

Andrea Brown
Chief Executive, NKF

Action Point

NKF Peer Support Service

Our NKF Peer Support Service is a free service aimed to support people who:

- Would like someone to talk to regarding the options of dialysis at home
- or have just started home dialysis and would like further support

For help, advice or just some reassurance, you are very welcome to contact us via our NKF Helpline for more information on **0800 169 09 36** available from 9am to 5pm Monday to Friday. For more information please visit our Peer Support web page [here](#).



"Learning to dialyse at home was one of the best decisions I have ever made as I can fit my peritoneal dialysis exchanges around my life and not the other way around."

I started home dialysis a week before the spring 2020 lockdown so it was great to dialyse in the comfort and safety of my home knowing that my home therapies team were always there if I needed their help.

Being on dialysis has had a big impact on both my physical and mental health, so having control of my own healthcare has been amazing."

- Alison Lawrence, NKF Peer Supporter

Contact the National Kidney Federation's FREE Helpline to speak to one of our trained home dialysis peer supporters based across the UK.

0800 169 09 36
www.kidney.org.uk

All Party Parliamentary Kidney Group (APPKG) Update

The inaugural meeting of the All Party Parliamentary Kidney Group (APPKG) took place on Monday 6th December 2021. The Chairman of the group is Brendan Clarke-Smith MP.

All-Party Parliamentary Groups (APPGs) are informal, cross-party, interest groups of MPs and peers interested in a particular issue.

The APPKG has been formed to improve the understanding in Parliament of kidney disease and transplant medicine and promote improvements in the health and care services that are available to improve the health of people with renal failure.

The National Kidney Federation performs the role of secretariat.

The first meeting of the newly formed group will take place in January 2022 with the subject being Covid-19 vaccinations, other meetings will take place in 2022 with home dialysis and transplantation being future agenda items.

Please see below the newly formed group:

Role	Name	Party	Constituency
Chair	Brendan Clarke-Smith MP	Conservative	Bassetlaw
Vice Chair	Gavin Newlands MP	SNP	Paisley and Renfrewshire North
Vice Chair	Sheryll Murray MP	Conservative	South East Cornwall
Vice Chair	Yasmin Qureshi MP	Labour	Bolton South East
Vice Chair	Barbra Keeley MP	Labour	Worsley and Eccles South
Vice Chair	Julie Elliott MP	Labour	Sunderland Central
Officer	Laura Farris MP	Conservative	Newbury

For more information about the group visit [here](#).

New to our In Touch newsletter issues, we want to explore the history of our Kidney Patient Associations (KPAs) by including a monthly feature dedicated to a specific region.

Northamptonshire Kidney Patient Association

For this issue Northamptonshire Kidney Patient Association Chairman, Jim Higgins discusses the history of his KPA.



Northamptonshire KPA was formed in 2005. We had to stop being a branch of the Six Counties KPA when all patients who lived in Northamptonshire were transferred to the University Hospital at Leicester.

Marion Higgins became the first secretary, Valerie Webster our first treasurer and Lewis Sander our Chairman and then successfully applied for charitable status. We started with a BBQ in our garden which raised £50.00 to open a bank account and together a merry band of patients and carers continued to help the cause.

We were lucky enough to win a "make a wish" competition run by the local newspaper and got £5k to buy a dynoscope for the only three dedicated renal beds in Northampton hospital (we now have the Northamptonshire renal suite) and at this presentation, Barclaycard adopted us as their charity of the year and raised £10k during that time.

The renal unit at Harborough Lodge in Northampton had a garden area and we made good use of that in the summer months with hog roast and fun days which had staff making cakes and selling them with games such as "Splat the rat" and old fashioned sack races. One "barbie q" had staff and patients dressed in pink!

Unfortunately this unit became too small and we had to find bigger premises but alas with no garden. We continue onwards today but the merry band has lost a few members and we would dearly like to attract more patients to join in with us, the staff at both units help with fundraising with a christmas raffle at each unit.

This year we have bought two caretray trollies for Kettering and have on order vital sign monitors for Northampton as well as helping patients with hardship grants and we also had a picnic in the park when the Covid restrictions allowed. We continue with our aims and are forever hopeful of a better outcome for kidney patients.

Jim Higgins
Northamptonshire KPA Chairman

New Editor Required for Kidney Life

The NKF is looking for a suitable person to take over as the Editor of the Kidney Life magazine.

The person may or may not have previous experience, however what is required is an interest in renal matters, and an empathy with renal patients – plus of course an engaging style of writing.

The magazine is published four times a year and consists of 24 pages per issue, a proportion of which are advertisements. Many of the stories contained in the magazine come from patients themselves who write to the editor, however equally the editor is expected to research and source stories of their own.

This is a paid position working from home, with a contract and agreed expenses will be met by the NKF.

If you are interested in applying please email nkf@kidney.org.uk or call 01909 544999 for further information.

Help Raise Awareness of Anaemia of CKD



Astellas, a pharmaceutical company, are looking for volunteers to share their story with the media. If you have been affected by anaemia as a result of chronic kidney disease and would like to raise awareness of its impact, then they would like to speak with you.

They are looking for volunteers who would consider:

- Speaking with Astellas to create a written biography to be sent to journalists
- Being available to be interviewed by journalists for use in newspapers or magazines
- Appearing on television or radio as part of a live interview

If you would like to get involved and would be interested in knowing more information please contact pete@kidney.org.uk.

COVID VACCINES EXPLAINED FOR KIDNEY PATIENTS

This information is for kidney patients to explain the schedule of Covid vaccines they should be receiving, and how to get the ones they need.

BOOSTERS

Booster doses are being offered to **everyone receiving dialysis treatment and those in chronic kidney disease stage 5 not yet on dialysis** (as well as all those aged 18 upwards). The usual vaccination schedule is two primary doses 8-12 weeks apart, followed by a booster three months after the second dose.



For these people three doses give a high level of antibodies, and a good chance of high protection from Covid-19.

THIRD DOSE FOLLOWED BY A FOURTH DOSE BOOSTER

There is a special vaccination schedule for patients who are immunocompromised. This is two primary doses, then a third primary dose given 8 weeks or more after the second dose and followed by a fourth dose booster three months after the third dose.



Four doses are being offered to **all kidney and other organ transplant recipients and many patients receiving immunosuppression for kidney disease and other conditions**. This is because **some immunosuppressed patients don't get an adequate antibody response after only three doses and need a fourth dose booster to give the best chance of high protection from Covid-19**.

WHICH VACCINE TYPE?

The booster, third dose and fourth dose booster are strongly recommended to be an mRNA vaccine (either Pfizer or Moderna), regardless of what the previous doses were, as this has been shown to create a more robust response.

AstraZeneca should not be used unless there is a good reason why an mRNA vaccine can't be given, for example due to an allergy. Specialist advice is recommended.

People having Moderna as their **third dose** need a **FULL DOSE**, whereas a half dose is given as a booster or fourth dose booster.

A **Flu jab** can be given before, after or at the same time as a booster, third dose or fourth dose booster and is recommended.

For more information on how to get the vaccine and other advice for the immunosuppressed, as well as information on patients eligible for four doses of the vaccine, please visit our [Covid-19 web page](#).

Melody Research Study

NHS Blood and Transplant are currently looking for organ transplant recipients to take part in a new research study, assessing the effectiveness of the COVID-19 vaccines.

The study aims to estimate how many immunosuppressed people in the UK have antibodies that may provide protection against COVID-19 after three vaccines and then assess whether people with antibodies have lower rates of infection and severe outcomes of infection than people without antibodies.

The results of this study may help assess the impact of the vaccines on the level of antibody response to COVID-19 across the UK and help guide public health policy towards vulnerable groups.

The study is looking for people aged 18 and over, who have received an organ transplant and have had the three COVID-19 vaccines to participate. Participation in the study would involve the below three steps:



STEP 1

- Login to the study portal
- Online consent and registration
- Questionnaire about your health



STEP 2

- Antibody kit delivered to your home
- You perform the antibody test



STEP 3

- Upload your results to the study portal
- Questionnaire about COVID
- Finish

To find out more and take part, please go to:

<http://www.melodystudy.org/regt> or call the freephone number **0800 819 9150**

You can also join the Melody Study Facebook group [here](#).

NKF Facemasks and Lanyards Available

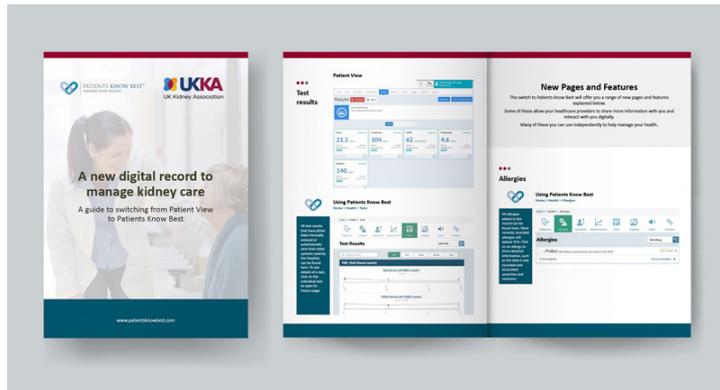
Our NKF black facemasks are made of soft cotton, very comfortable to wear, and have a small NKF logo and the best bit is - they are **only £1.50 each plus postage!**

We also have in stock social distancing lanyards at **£1.00 each plus postage.**

To order facemasks or our social distancing lanyards please visit [here](#) or call 01909 544999 where you can place your order and we can take payment by card.



Patients Know Best



The UK Kidney Association (UKKA), formerly the Renal Association, has signed an important agreement with Patients Know Best (PKB) to move PatientView to the PKB personal health records system.

This will improve the existing security and functionality of the current PatientView system, which was one of the first patient portals in the UK.

The new system offers people with kidney disease and their care teams advanced features and functionality, including increased security, care planning, team-based messaging and an ecosystem of integrated wearable and monitoring devices to support clinical transformation.

To support people throughout the transition of moving from PatientView to PKB, a [comprehensive guide](#) has been created on how to use the new system and where to find patient data and records.

The transition from PatientView to PKB commenced at the end of October 2021. Any previous patient data, as well as new data, such as test results and measurements, is available in your PKB record once your local renal unit has been switched over.

The list of renal units who are now live will be updated weekly here: [Look up your unit](#)

You will not be able to see your renal patient data on the new system until the renal unit you are connected to has switched to PKB. If you are a patient in England, you will be able to register for PKB using the new user function on [NHS Login](#). For more details on how to activate your account [click here](#).

Patients in Wales will be contacted by email or letter once the contract with Wales and PKB is in place. This is likely to be in early 2022. If you are a patient in Scotland or Northern Ireland, your local unit will be in touch via email or letter to confirm when and how to register.

If you have any questions, please [contact the PKB support team](#).

The New Chiltern Kidney Centre

25th November was a great day for the Lister Area Kidney Patient Association (LAKPA) as it saw the official opening of a brand new kidney centre in Dunstable. The new unit has 23 open stations, 8 side rooms, 4 shared care areas, 6 consultation rooms, as well as staff rest areas, training and quiet rooms and cleaning and maintenance areas.

The building was opened by Ellen Schroder, Chair of the North and East Herts NHS Trust and Kirit Modi chair of LAKPA. Kirit said "We are delighted the new centre is open. It has excellent

facilities, and our aim is to establish a wide range of high-quality services for kidney patients by working in partnership with the Trust, so that it becomes one of the best in the UK." Tony Heath, who has been an amazing patient representative on the project team for many years said how delighted he was that the project had come to fruition in this way. The excellent facilities will enable kidney patients from Luton and Dunstable to access better services locally.



In 2018 a funding bid to the Department of Health was successful, a suitable site was identified, a contractor appointed, and the work was completed at the end of September 2021, ready for the first patients to start dialysis in early October. Thanks to the hard work of all the staff the move went well, and dialysis started successfully on October 11th. Once all the dialysis patients are settled in, other services will start to be introduced to deliver the truly transformational unit that has been planned.

LAKPA has been involved and consulted throughout the process and has worked with the project team in bringing the patient's voice to the process. Ros Aird, LAKPA Secretary has worked closely with the Trust's communications team in ensuring that patients, staff, carers and families were kept fully informed of the process of moving the operation, through leaflets, webinars and dedicated emails for queries. Ros said "The co-operation and goodwill of all involved, and the positive reactions from the patients and carers have made it a pleasure to be involved in this project".

All the staff at the old unit have transferred and they are delighted with the space and peaceful ambiance that the unit provides - as one of the nurse managers said - "It may be further for me to travel, but it is so worth it". Patients too have expressed their appreciation, as one said "I don't know how it could be better".

The final word should come from Dr Praveen Jeevaratnam, the Trust's Clinical Director for renal medicine who said "I could not be prouder of the team who have worked so hard to deliver this landmark project. Thanks to their determination and collaborative approach, we have a state-of-the-art unit that is patient centric and a model for future developments".

Patient Participation Opportunities

Hyperkalaemia - Patient Filming Project

Hyperkalaemia is a serious condition that negatively impacts patient quality of life and is potentially life-threatening, causing fatal cardiac arrest and muscle paralysis. Up to 73% of advanced Chronic Kidney Disease (CKD) and 40% of chronic Heart Failure (HF) patients may be at risk of hyperkalaemia.

As part of Vifor's commitment to supporting improved patient outcomes for HF and CKD, we are producing a series of four short patient films and one feature film to empower patients to lead conversations around hyperkalaemia diagnosis and management with their Healthcare Professionals (HCPs). The films will be sponsored in full by Vifor Pharma UK Ltd. Once produced, we will distribute the films via Vifor and patient group social and digital channels to help educate patients with HF and CKD.

To help identify patients to be involved in filming, below is an overview of the patients needed and an indication of what questions they may be asked if they choose to participate as well as expected time commitments.

Patients will be provided with a full brief and consent form ahead of filming.

Patients required:

- Four adult patients with hyperkalaemia (aged 18+)
- The patients should historically have had high serum potassium levels (assuming >5 mmol/L) but now be well managed

To ensure good representation, patients should be identified:

- from both CKD and HF patient groups
- from a variety of ethnic backgrounds
- mix of genders
- cross selection of adult age groups
- from across the UK (North, South, East, West England and/or Scotland, Wales, Northern Ireland)
- If possible, we would like to include a patient who has had an emergency hospital admission for acute severe hyperkalaemia

What will be involved:

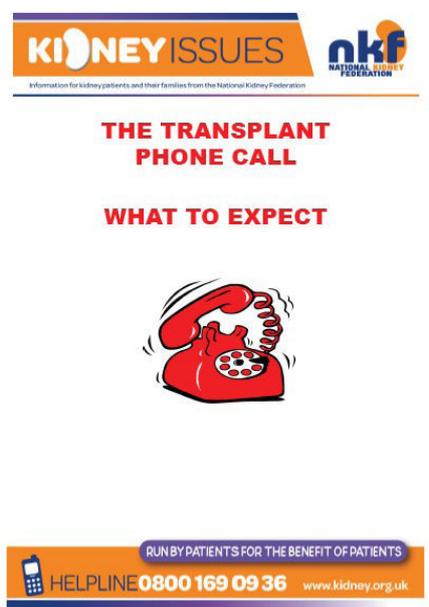
- Patients and their family members (if willing) will be filmed remotely via Zoom.
- Patients will be briefed in advance so they know what to expect and a production team will be on-hand at the briefing session and at filming to provide technical assistance.
- A camera and microphone will be sent in advance as needed and patient's will be fully supported technically throughout
- Patient's will be asked to describe their journey, from being told they had hyperkalaemia, to the adjustments that they have had to make to their lives, and the challenges they face(d)
- Patients will be encouraged to share their experiences in an emotive way

Please contact Pete Revell on pete@kidney.org.uk if interested in taking part.



NEW LEAFLET FROM THE NKF HELPLINE

The Transplant Phone Call: What to expect



A call for a kidney transplant can come at any time but are you prepared and do you know what to expect once you have got the call?

Our new leaflet will explain what you will need to do when you get "the call", as well as what you will need to take with you to hospital and what to expect when you arrive.

To request a copy of this leaflet or if you are a renal unit and would like several copies, please contact the NKF Helpline on **0800 169 0936** or e-mail helpline@kidney.org.uk.

If you would like a full list of our patient information leaflets and information packs please contact the NKF Helpline on the above number.

Did you know the helpline is also available to reach online? Visit our website to use our live chat service on www.kidney.org.uk.

NKF Fundraising

As the year comes to an end, we look back on another year of fantastic support, we had the NKF Water Challenge, Best Foot Forward Step Challenge and Choctober, from this we have seen record amounts of fundraising efforts raised for the charity. We have also seen individual fundraising from people doing marathons, sky dives! We would like to say a big thank you to everyone that has took part in our challenges or donated.

The charity has helped more kidney patients than ever this year, and we couldn't have done it without your support!

I hope you have a wonderful Christmas and Happy New Year.

Pete Revell,
Head of Marketing & Fundraising

THANK
YOU

The NKF Calendar 2022 *Limited Stock*

Our NKF calendar for 2022 is still in stock at a new reduced price of just £3.00!

Including twelve photos of locations from across the UK and space to write your reminders.

Order yours today [here](#) via the online shop or call 01909 544999 where you can place your order and we can take payment by card.



2022
CALENDAR

Follow us on social media



The NKF – the largest Kidney Patient Charity in the UK

A FEDERATION OF MORE THAN FIFTY PATIENT CHARITIES, SUPPORTING KIDNEY PATIENTS & CARERS

Registered Office: The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

Registrations: Registered in England & Wales, Charity Number: 1106735, Scottish Charity Number: SC049431.

Company Number: 5272349. Give as You Earn contributions number: CAF GY511.